The Needs of Individuals With Disabilities in Oklahoma

Esther I. Wilder
Department of Sociology and Social Work
Lehman College, City University of New York

This research was generously sponsored by the Oklahoma Office of Handicapped Concerns (OHC). I am especially grateful for the support and encouragement of Steven Stokes, the Director of OHC. Traci Kane and Stacey Hansen meticulously coded the results from the questionnaires and Morgan Lindsey provided helpful research support. William Walters' careful review of this report was especially appreciated. The names of individuals with disabilities have been changed to protect the confidentiality of participants in this study. This project would not have been possible without the support of dozens of organizations throughout the state that provide services to individuals with disabilities. I am grateful to every one of them. The opinions expressed in this report do not necessarily represent the views of the State of Oklahoma, the Oklahoma Office of Handicapped Concerns, or the agencies that cooperated in distributing the surveys.

June 2002

Table of Contents

The 2001-2002 Oklahoma Disability Study

This report is based on data obtained from the 2001-2002 Oklahoma Disability Study (ODS), a statewide survey that solicited information on the economic, medical, therapeutic, social, and vocational needs of individuals with disabilities in the state of Oklahoma. According to the Americans with Disabilities Act (ADA), an individual is considered to have a disability if he or she (1) has a physical or mental impairment that substantially limits one or more major life activities, (2) has a record of such impairment, or (3) is regarded as having such an impairment.

ODS surveys were distributed to four groups of Oklahoma residents: individuals with disabilities, the parents of children with disabilities, the close relatives of individuals with disabilities, and the directors or presidents of organizations that provide disability-related services. While all respondents received the same set of questions regarding their personal characteristics, disabilities, and needs, the survey forms sent to directors/presidents included additional questions pertaining specifically to disability-related organizations. (The cover letter sent to disabled individuals, their close relatives, and personal caregivers is reproduced here as Appendix A. The survey form sent to directors and presidents is presented as Appendix B.)

The questionnaires were distributed in cooperation with public and private agencies throughout the state. Many disability-related organizations agreed to share their mailing lists with us; in those cases, survey forms were sent to every person listed. Other organizations offered to mail the questionnaires to their members and clients on our behalf. Some respondents picked up survey forms at the events or meetings of local organizations, while others requested surveys or completed the online questionnaire after reading or hearing about the study in the media. (The Oklahoma Disability Study was covered by eleven local newspapers and one television station.) The various methods of distributing the survey are described in more detail in Appendix C.

The survey was made available in a variety of formats including regular print, large print, Braille, audiotape, and online. While we distributed over 9,000 surveys, approximately 500 were returned due to incorrect addresses, deceased addressees, or similar circumstances. We do not know the exact number of undelivered surveys, however, since some were returned to the participating organizations rather than the survey team. Moreover, some organizations may not have distributed all the surveys we provided. (We did, however, follow up with all organizations that requested 300 or more surveys, and in only one case did we have to remind the agency to distribute the questionnaires.) It is also likely that some of the individuals on our mailing lists did not meet the eligibility requirements for participation in the study.

Altogether, 1090 surveys were returned, and an additional 54 were completed online. Of this total (1144), 599 (52%) were completed by individuals who themselves had disabilities (including ten directors/presidents of organizations that provide disability-related services); 326 (29%) were filled out by parents of children with disabilities (including five directors/presidents); 72 (6%) were completed by close relatives of individuals with disabilities (including four directors/presidents); 52 (5%) were filled out by personal caregivers of individuals with disabilities (including one director); and 15 (1%) were completed by able-bodied directors/presidents who were not closely related to any individuals with disabilities. The remaining 80 respondents (7%) provided no identifying information. Of the 599 individuals with disabilities who completed the survey, 119 (20%) reported that someone had assisted them in filling out the questionnaire. Of the 1144 surveys we received, 453 (or 40%) contained some written comments from the open-ended portion of the questionnaire.

A handful of surveys (n=11) was returned by respondents who reported that they didn't meet the eligibility requirements or did not want to participate in the study. Because we do not know the exact number of surveys distributed to eligible recipients, we cannot calculate a response rate for this study. Moreover, a significant number of the returned surveys were only partially completed. At the same time, however, our sample does include respondents with a wide range of personal characteristics — different types of disability, levels of income, areas of residence, etc.

Characteristics of the Sample

Table 1
Type of Disability, by Race/Ethnicity and Gender[a]

	Race/Ethnicity					Gender		
	White	Black	American Indian	Asian[b]	Latino(a)	Male	Female	Total
% Visual impairment	17.8	16.9	21.5	55.6	28.6	14.8	22.5	18.6
% Hearing impairment	23.2	15.3	25.2	33.3	21.4	22.5	24.2	23.0
% Mobility impairment	33.2	25.4	33.6	11.1	42.9	32.2	33.6	33.0
% Neurological impairment	30.2	13.6	25.2	33.3	35.7	31.1	26.2	28.9
% Psychological impairment	13.9	10.2	17.8	0.0	14.3	14.2	13.6	13.8
% Speech impairment	19.8	16.9	17.8	11.1	42.9	20.7	19.2	19.6
% Learning disability	18.3	22.2	25.2	0.0	35.7	20.7	18.5	19.2
% Mental retardation	18.4	18.6	14.0	0.0	50.0	16.9	19.8	18.2
% Chronic illness	19.3	22.0	14.0	0.0	28.6	16.3	22.1	18.9
% Other disability	14.7	27.1	18.7	0.0	21.4	17.5	13.6	15.7
Average # of disabilities[c]	2.1	1.9	2.1	1.4	3.2	2.1	2.1	2.1
n	880	59	107	9	14	521	530	1077

[a] These data reflect the status of the disabled individual, even if someone else completed the survey on his or her behalf.
[b] Includes Pacific Islanders.
[c] The disability categories are not mutually exclusive. In fact, 52% of disabled individuals have two or more disabilities. The response option "other disability" was counted as a single disability in these calculations.

Table 1 shows the demographic characteristics of the respondents in our sample. While whites and blacks report similar types of disabling conditions, whites are somewhat more likely to experience hearing problems and neurological impairments. Latino respondents are especially likely to report mobility and speech impairments, whereas Asians have notably high rates of visual impairments. Males are especially prone to neurological disabilities while females are more likely to experience chronic illness and visual impairments.

Table 2
Occurrence of Multiple Disabilities, by Type of Disability and Age[a]

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% Visual imp.	-	24.6	23.4	19.0	22.1	30.8	22.7	23.0	18.6	16.0	-
% Hearing imp.	30.5	-	12.7	9.6	16.8	34.1	18.8	14.3	14.7	11.8	-
% Mobility imp.	41.5	18.1	-	51.4	26.8	44.5	36.2	28.6	40.7	23.7	-
% Neuro. dis.	29.5	12.1	45.1	-	44.3	36.0	38.6	28.1	34.3	21.3	-
% Psych. dis.	16.5	10.1	11.3	21.2	-	17.1	27.1	14.8	16.7	18.9	-
% Speech imp.	32.5	29.0	26.5	24.4	24.2	-	49.8	48.0	13.2	13.0	-
% Learning dis.	23.5	15.7	21.1	25.7	37.6	48.8	-	41.3	12.3	17.2	-
% Mental ret.	22.5	11.3	15.8	17.7	19.5	44.5	39.1	-	8.8	11.2	-
% Chronic ill.	19.0	12.1	23.4	22.5	22.8	12.8	12.1	9.2	-	20.1	-
% Other	13.5	8.1	11.3	11.6	21.5	10.4	14.0	9.7	16.7	-	-
Age											
% <18	19.3	27.6	15.3	19.3	19.6	40.8	37.1	36.1	8.5	25.0	20.6
% 18 to 64	63.5	56.0	70.6	74.4	77.7	53.4	62.0	62.9	77.1	71.4	69.2
% >64	17.3	16.5	14.1	6.2	2.7	5.8	1.0	1.0	14.4	3.6	10.2
Average Age	42.5	38.3	42.2	37.4	34.1	26.8	24.8	24.6	44.7	44.7	37.6

[a] Read down the appropriate column, then across to the row heading. For example, 40.7% of those with a chronic illness also reported a mobility impairment; 23.4% of those with a mobility impairment also reported a chronic illness.

The majority of the respondents in our sample (52%) have more than one type of disability. The incidence of multiple disabilities is especially high among Latinos, who report an average of 3.2 different disabling conditions. (See Table 1.) Table 2 shows the kinds of disabilities that are most likely to occur together. The most common multiple disabilities are neurological and mobility impairments. In fact, over half of the respondents who indicated neurological disabilities also reported impaired mobility. Similarly, almost half of the respondents with learning disabilities or mental retardation also had speech impairments. Forty-four percent of those with psychological disabilities also reported neurological disabilities.

Table 2 also shows the age distribution of respondents with each type of disability. While learning disabilities and mental retardation are especially common among younger respondents, individuals with visual impairments and chronic illnesses are considerably older, on average.

Concerns of Survey Respondents

Table 3
Family Income[a]

	Family size					
	1	2	3	4	5+	Total
% No income	12.3	3.5	4.5	4.6	4.6	4.8
% Less than $5,000	13.0	7.0	5.8	5.2	6.9	8.6
% $5,000 to $9,999	33.0	15.0	9.7	12.1	13.2	18.3
% $10,000 to $14,999	13.4	16.3	12.9	9.2	11.5	13.6
% $15,000 to $24,999	11.5	21.6	18.7	12.6	9.2	15.1
% $25,000 to $34,999	5.7	13.2	11.6	16.7	10.9	11.2
% $35,000 to $44,999	3.4	8.8	10.3	9.8	13.8	8.7
% $45,000 to $54,999	4.6	5.3	7.1	12.6	8.0	6.8
% $55,000 to $74,999	1.9	7.0	9.0	6.9	10.9	6.8
% $75,000 to $99,999	0.8	0.9	5.8	6.9	4.6	3.3
% $100,000 or more	0.4	1.3	4.5	3.4	6.3	2.9
Median	$8,760	$18,775	$24,509	$30,172	$29,210	$18,133
n	261	227	155	174	174	943
Missing	34	28	19	28	15	100

[a] Includes individuals/families in which at least one member has a disability.

Economic hardship is a constant concern for many individuals with disabilities. This single factor keeps many disabled individuals and their families from realizing even their most basic needs. Table 3 shows, for example, that ODS respondents living alone have a median annual income of just $8,760.[1] Twenty-five percent of these respondents have annual incomes of less than $5,000. Moreover, the situation is no better in multi-person families; the families in our sample have a median annual income of $18,133. In comparison, the median annual income of *all* Oklahoma households was $33,235 in 1999-2000. That same year, the median U.S. household income was $42,168 (United States Census Bureau 2001).

---

[1] These figures are interpolated estimates, since income ranges (not precise values) were used in the 2001-2002 ODS.

Table 4
Receipt of Government Assistance, by Type of Disability

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% SS retirement	16.5	17.3	14.1	4.8	1.3	6.2	2.4	0.5	13.7	3.6	10.2
% SS disability	35.5	24.2	40.3	42.8	38.9	30.8	32.9	28.1	40.7	36.7	33.3
% SSI	34.5	28.2	27.3	29.6	34.9	36.0	40.1	50.5	26.0	25.4	27.4
% Voc. rehab	4.0	3.2	5.1	2.9	2.7	1.9	2.9	1.5	4.4	3.0	3.5
% Work comp.	0.5	1.2	1.1	1.9	0.7	0.9	1.0	0.0	1.0	0.0	0.7
% Food stamps	12.0	10.9	13.5	9.6	24.8	8.5	9.7	9.2	23.5	21.9	13.4
% Medicaid	37.0	25.4	37.7	35.0	45.6	43.6	49.8	50.5	30.4	32.5	30.1
% Medicare	37.0	27.8	36.1	26.7	22.8	23.7	20.3	21.4	36.8	25.4	26.4
% Other	15.0	10.9	17.5	18.6	16.1	14.7	14.0	14.8	20.6	17.8	14.6
% Any assistance	86.0	72.6	84.2	80.4	81.9	79.1	81.6	83.2	86.8	77.5	76.1
n	200	248	355	311	149	211	207	196	204	169	1077

Table 4 shows the percentage of respondents receiving various forms of government assistance. Seventy-six percent of Oklahoma residents with disabilities receive some form of financial support. As might be expected, those with old-age disabilities such as chronic illness are most likely to be collecting Social Security retirement benefits. Conversely, respondents with mental retardation or learning disabilities are especially likely to receive Supplemental Security Income (SSI) payments.

The Necessities of Life

Many respondents experience considerable difficulty in their efforts to pay for basic human needs such as food, clothing and shelter. This sense of financial distress is especially acute among individuals or parents of individuals with chronic disabilities. For example, the mother of an eight-year-old girl with quadriplegia (family size of 3; income between $10,000 and $14,999) wrote,

> I receive $86.00 in food stamps. This is not enough for a family of 3. I receive TANF. After my 5 yrs. are up, I will no longer receive this. This concerns me. When this stops, I will not be able to support my family, which I barely can now. I am not able to work, because I am a 24 hr. nurse for my daughter. She is a quad and on a ventilator for life support.

Table 5
Responses:
Social Security Disability Insurance and Supplemental Security Income (SSI) provide adequate financial help to disabled individuals who cannot work

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.1	3.2	1.3	1.1	2.2	1.0	0.5	0.5	1.6	1.4	2.1
% 2	0.0	0.5	0.0	0.7	0.7	0.0	0.0	0.0	0.0	0.0	0.4
% 3	1.6	5.5	2.6	1.8	0.0	3.0	2.1	1.6	2.1	0.7	3.2
% 4	7.7	11.1	8.7	10.0	5.8	13.4	9.3	13.1	4.8	9.0	10.2
% 5 (Very important)	89.6	79.7	87.5	86.5	91.2	82.7	88.1	84.7	91.4	88.9	84.2
Mean	4.8	4.6	4.8	4.8	4.8	4.8	4.8	4.8	4.8	4.8	4.7
n	183	217	312	281	137	202	193	183	187	144	974
% 1 (Not satisfied)	44.7	35.2	41.4	42.1	49.6	36.4	39.0	39.1	46.1	44.1	37.2
% 2	16.5	21.2	21.2	20.1	15.5	21.9	19.2	21.9	21.1	17.6	22.3
% 3	20.0	23.3	21.9	24.5	18.6	25.7	21.5	20.7	18.3	26.5	24.1
% 4	8.8	5.7	7.4	7.3	7.8	8.0	10.7	8.9	6.1	6.6	8.3
% 5 (Very satisfied)	10.0	14.5	8.1	5.9	8.5	8.0	9.6	9.5	8.3	5.1	8.0
Mean	2.2	2.4	2.2	2.1	2.1	2.3	2.3	2.3	2.1	2.1	2.3
n	170	193	297	273	129	187	177	169	180	136	895

As Table 5 shows, the overwhelming majority of respondents think it is very important that SSDI and SSI provide adequate financial support for disabled individuals who cannot work. At the same time, fewer than 17% are satisfied that this need is being met. There is little variation in attitudes by type of disability, although individuals with hearing impairments are somewhat less likely than others to stress the importance of this need. (Hearing-impaired individuals are also less likely to be receiving SSDI. See Table 4.)

Many respondents feel that the government does not have a genuine concern for their financial or physical well-being. For example, a 37-year-old man with several disabilities (visual, hearing, neurological, psychological, learning and a chronic illness) and a personal income of less than $5,000 (SSI and Food Stamps) wrote,

> People that are disabled [cannot] make ends meet on what the S.S. Adm — pays — can't barely eat or pay for medications — or even buy a new pair of shoes or not even clothing — or necessary items — to live in a [healthy] environment. ... D.H.S [doesn't] really care if you can eat or pay utilities or pay for medication.

Likewise, a 43-year-old man with a variety of disabilities (mobility, neurological, and chronic illness) who had a personal income between $5,000 to $9,999 (SSDI) wrote,

> I feel the state of Oklahoma should be [ashamed] ... They [believe] a person with a disability can live, buy food, prescription drugs and pay for it on less than a income of $1,000 [per month].

Another respondent reported that SSDI and SSI provide adequate financial help to individuals with disabilities, but "only in unsafe/poor neighborhoods." Echoing this sentiment, a 46-year-old female SSI recipient with a variety of disabilities (visual, hearing, neurological, psychological and chronic illness) and a personal income between $5,000 and $9,999 reported,

> I am now paying 60% of my income to live in a house that the poverty & crime rate is much higher [than my previous home]. I have been broken into already. The house is about half the size of where I moved from and is low quality — the plumbing has been making me...ill most of the time I have lived here.

Many of the respondents' written comments convey an acute sense of financial desperation. Perhaps not surprisingly, several respondents wrote that they are teetering on the brink of homelessness. For example, a 35-year-old man with AIDS in Oklahoma County (2000 personal income between $5,000 and $9,999) wrote,

> No rent assistance except from Care Point [an organization that provides assistance to individuals who are HIV positive] then that rug is yanked after 24 months. .... Now I face homelessness with a whopping income of: SS $560, Food stamps: $124, DHS $24, Monthly pay check $206, total $770. Can you live on that? Deposits, transfer fees, incidentals...Good luck! It's pathetic! We are sick <u>AND</u> FORCED to live <u>BELOW</u> poverty level.

A number of respondents also feel that the food stamp program fails to provide adequate assistance. For example, a 54-year-old woman with a chronic illness (2000 personal income between $5,000 and $9,999) wrote,

> [There is a] problem of inadequate income in respect to receiving food stamps. A food stamp allowance of $10.00 doesn't help [a lot] when your monthly income is $584.00 [—] well below [the] poverty level & yet an ordinary person capable of working is allowed $130.00 monthly.

Many respondents agree that the government makes it difficult, if not impossible, to support one's self or one's family strictly on the assistance provided. As a result, it becomes necessary to supplement one's income — sometimes through illegal means. A 41-year-old man with a neurological impairment (personal income between $5,000 and $9,999) wrote,

> In 1982 my neck was broken and shortly, life began again. Not able to work I received SSD to live on, could not do so, so my income was supplemented by selling drugs, not <u>using</u> <u>them</u>. This endeavor was a <u>success</u> and living comfortably was possible. After years this practice stopped, the Lord intervened. The same is still a lifestyle for many with a disability.

Financial difficulties were also voiced by several individuals who were *not* receiving any form of government support. A 34-year-old woman with a chronic illness and no income assistance expressed her concerns:

> The state of Oklahoma does not pay SSI well enough for someone who is dying — so I have to continue to work 85 hrs. a week to support my family till my heart just stops beating. I do not [believe] this is right. My family wants me home so I receive the rest I need. The doctor

> wants me to rest more! But no one cares whether you have to file bankruptcy and lose everything, even your respect for yourself.

Similarly, a 23-year-old man (family income between $5,000 and $9,999, no financial assistance) wrote,

> I feel that there is not enough help out there when you need it. Myself & my lover have been living the last 5-6 months with the HIV virus. We have been struggling to keep the rent paid, bills [paid], and food in the pantry. I work two jobs, and still have problems getting ahead and [it's] frustrating. Not only do I have to deal with living with HIV, I have to worry about [whether] society is going to swallow me whole.

Eligibility Rules for Governmental Financial Support

Many ODS respondents feel that the eligibility thresholds for government assistance are unrealistically low. In fact, 57 respondents, or 13% of those who provided written feedback, voiced concerns relating to these eligibility rules. The close relative of a 50-year-old woman with a hearing impairment (2000 family income between $15,000 and $24,999; family size of 4) wrote, "The financial issue seems to be the hardest on our family since my mother can no longer work. SSI is very hard to get." Similarly, a 24-year-old woman with a learning disability (family income between $75,000 and $99,000; family size of 4) wrote, "Since there is an insane limit [for government-sponsored financial and health care programs], I could not qualify since I and my parents 'earn too much' by state/fed standards. But I believe this program is very important. I will vote for an increase in taxes to further fund programs like these."

Some respondents feel that financial support should be expanded to cover a broader range of conditions, and that the eligibility requirements should be less stringent for those with developmental disabilities. For example, the parent of a 16-year-old girl with psychological and learning disabilities wrote,

> My child has had no schooling, no job skills, and is 3 points from being [mentally] retarded so she [doesn't] get any services from DDSD [Developmental Disabilities Services Division].[2] And she turns 17 in a few weeks. So how do you think she will be able to live when she is on her own [?] Or if she is getting any closer to getting off SSI. I have been told when her IQ drops 3 more points she can be [considered] mentally retarded, then she can get services. So there [are] services when you get bad enough. But why do you have to reach that point first, while your life is going by now [?]

Other respondents are frustrated by the fact that they or their children had been denied benefits *in spite of* their disabilities. For example, a 58-year-old woman (2000 family income between $45,000 and $54,999; family size of 2) wrote,

> My major complaint is regarding Social Security Disability. I was told before applying [that] it was a waste of time unless you were terminal or a minority — which I found to be true. I have scleroderma with an overlap of Lupus. I had to retire at age 56 on the recommendation of 3 doctors — yet I was denied Social Security.

Likewise, the parent of a 14-year-old girl (income between $35,000 and $44,999; family size of 4) wrote, "Daughter also has been turned down several times for SSI — seems you must be blind or paralyzed to get help. Guidelines are far too strict when a child with spina bifida cannot get help." A 48-year-old man with AIDS (income between $5,000 and $9,999) wrote, "Why is it when you apply for SSI or any help, they make you feel like [you're] begging, when you actually paid it in. I have aids [sic], was denied — I have re-applied we'll see now. I wonder how bad things have to get health-wise before help arrives."

---

[2] The Developmental Disabilities Service Division (DDSD) of the Department of Human Services provides services to people with mental retardation, autism or cerebral palsy. State law defines a person with mental retardation as someone affected with mental defectiveness from birth or an early age to such an extent that he is incapable of managing himself or his affairs and who requires supervision, control, or care for his own or others' welfare. The person's disability must result in substantial functional limitations in three or more areas of major life activity (Oklahoma Statute §10-1408). "Dean Bond, a DDSD case manager, says the division usually uses an IQ of 70 as its eligibility cutoff, but that it is not an absolute determinant. In some cases, particularly where a person has a secondary diagnosis such as a physical disability or mental illness, DDSD will grant eligibility to a person whose IQ is up to 75. The diagnosis must be made before the person's 21st birthday" (Kasprak and Spigel 2000).

A few respondents provided justification as to why they (or their children) deserved benefits in spite of denials from the government. For example, the parent of a 25-year-old woman (income between $15,000 and $24,999; family size of 2) wrote, "My daughter is developmentally retarded. She was denied SSI because she can work, but the only jobs she can get are part time jobs at minimum wage." Similarly, a 29-year-old woman with a variety of disabilities (neurological, psychological, chronic illness and other) and a 2000 family income between $15,000 to $24,999 (family size of 2) wrote,

> I don't think that it is fair to be denied assistance from SSI or SSD because I can walk. That doesn't mean that I don't need help with my medical bills and to be able to see a doctor when I need to without having to go to the emergency room.

Another respondent, the grandparent and personal caregiver of a 20-year-old woman with a learning disability, believes strongly that governmental support should extend throughout the life course:

> Why is a disabled person automatically deemed no longer learning disabled after they turn 18 yrs. or so? They do not automatically become well!!!! My granddaughter has been learning disabled all her lifetime. She works very hard to overcome her problems. We have now been on appeal with SSI for over a year because she reached 18 yrs. When our appeals are exhausted she will also no longer qualify for aid from other agencies if we are denied. They are telling us she is borderline so it could go either way. One of the big things against her is that she is trying and working so hard to overcome her disabilities. If she would just sit back & not try she could easily qualify, i.e., not try furthering her education, studying many, many hours with lots of help from family to pass tests, etc. I feel she is discriminated against because she [cannot] get help while she is trying so hard to help herself.

Several respondents suggested that the financial criteria used to determine eligibility for SSI should be changed: some argued that eligibility for SSI benefits should be made on the basis of a family's *net* rather than *gross* income. For example, the parent of a one-year-old girl with Down Syndrome (family income between $35,000 and $44,999; family size of 4 and no financial assistance) wrote,

> I think it is a travesty that children with disabilities can't [receive] SSI because of their parents' income! For example, my 1 ½ year old daughter got cut off from SSI & medical because our income went up to $38,000 a year. But when she turns 18 years she'll get SSI/medical no matter what our income is! She has Down Syndrome. .... At best [government officials] need to go by these families' <u>NET</u> income to see if they qualify for these programs. Officials don't realize the things these children need every month and programs that have to be paid out of pockets that cause us to be broke or our children go without every month. .... If they just went by <u>NET</u> income...they could save [a lot] of people from [financial] hardships & bankruptcy because it is that expensive!

Similarly, a 40-year-old woman said she was "tired of trying to get help" for "food, med, [or] doctor co-payment." As a result of her financial difficulties, she complained that she was "always stressed." She stated, "They don't give you help because of the gross income."

Health Care Coverage

Table 6
Responses:
Insurance companies do not discriminate on the basis of disability

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	0.0	1.8	1.3	2.1	0.7	1.5	1.0	1.1	1.1	0.7	1.7
% 2	0.0	0.4	0.3	0.7	0.0	0.0	0.5	0.0	0.0	0.7	0.4
% 3	1.6	2.7	1.9	4.6	3.0	2.5	2.6	0.5	3.2	2.1	3.3
% 4	8.2	13.3	5.1	6.3	9.7	10.6	8.4	7.7	8.6	7.7	8.2
% 5 (Very important)	90.2	81.9	91.5	86.3	86.6	85.4	87.4	90.7	87.1	88.8	86.4
Mean	4.9	4.7	4.9	4.7	4.8	4.8	4.8	4.9	4.8	4.8	4.8
n	184	226	316	284	134	198	191	182	186	143	980
% 1 (Not satisfied)	45.9	35.0	52.4	48.3	46.1	45.9	50.0	50.3	57.0	54.9	46.3
% 2	17.1	18.7	20.3	22.3	18.8	18.0	18.8	18.7	15.1	12.0	16.8
% 3	24.1	25.6	17.6	19.7	17.2	27.3	18.2	22.8	19.6	21.1	23.6
% 4	4.1	10.8	4.7	4.5	7.8	3.8	6.3	4.7	4.5	3.8	6.7
% 5 (Very satisfied)	8.8	9.9	5.1	5.2	10.2	4.9	6.8	3.5	3.9	8.3	6.7
Mean	2.1	2.4	1.9	2.0	2.2	2.0	2.0	1.9	1.8	2.0	2.1
n	170	203	296	269	128	183	176	171	179	133	899

Of all the needs mentioned in the 2000-2001 Oklahoma Disability Study, health care needs — especially insurance coverage for medical care — were ranked as the most important overall. In their written comments, for example, 55 respondents (12% of those who provided written feedback) voiced concerns relating specifically to health coverage. As Table 6 shows, respondents overwhelmingly felt it was very important that "Insurance companies do not discriminate on the basis of disability." The majority of ODS respondents also reported that their needs in this area were not being met.

Several respondents complained that insurance companies actively discriminate against individuals with disabilities. A 42-year-old woman with several disabilities (mobility, neurological, chronic illness and other) responded to the question by stating, "This is happening to me!" Similarly, a 28-year-old man with a variety of impairments (visual, mobility, neurological, speech, learning and chronic illness) reported that his insurance company had "tried to drop" him. This sentiment was repeated by the mother of a 14-year-old girl with a variety of disabilities (psychological, chronic illness and other):

> Disabled person's mother (myself) was laid off from job because company was self-insured. They felt I used the health insurance benefits too much — because of child with spina bifida.

Quite a few respondents described the challenges they faced in obtaining medical coverage for themselves and their children. For example, the parent of a 9-year-old girl with multiple disabilities (mobility, neurological, speech, learning, mental retardation and chronic illness) wrote,

> The waiver [services][3] provide a limited amt. of resources but out of the $11,700/year it has to cover HTS [Habilitation Therapy Specialist services][4] at over $12.00/hr; equipment (physical and speech), adaptations to home & transportation, and diapers, etc. ... It is impossible to cover all of that with that amount, and as I previously stated, ins. doesn't cover it either. <u>And</u> Ins. Comp. do <u>DISCRIMINATE</u>! Especially PacifiCare.

Similarly, a 47-year-old man with a neurological disability and a chronic illness wrote, "Affordable life insurance [for people who are HIV positive or who have AIDS] or extra insurance coverage [is] still not available." Another respondent, a 25-year-old woman with several disabilities (hearing impairment and chronic illness), described her struggles to meet her health care needs:

> I was born with cleft [palate] which was not found [until] I was 3 because I wasn't talking. At that time they found hearing loss also. I have had multiple surgeries, 10 yrs. of speech [therapy] and [I am] still in & out of the [doctor's] office. I struggled in a public school and continue to struggle in college. I am deaf in [my] right ear and wear 2 hearing aids. [Crippled] children's insurance [stopped] helping [to pay] for [doctors'] bills after I was 18 yrs old. It seems I can never get my medical bills caught up. As for now, I am unemployed because my employer was upset about me not telling him about my hearing at my interview. So I am again left w/ out insurance again.

Respondents overwhelmingly feel that far too many individuals fall through the cracks and therefore lack adequate medical coverage. For example, the parent of a 12-year-old boy with neurological and learning disabilities wrote,

> My concerns are around medical coverage for children with disabilities. It should not [solely] be determined on whether a child is on SSI .... Insurance is extremely high for a child with a disability and insurance companies don't always cover the needs of a disabled child.

---

[3] Waivers allow the state to offer home and community-based services in place of the institutional services to which clients would otherwise be entitled. They also allow individual clients to choose home and community-based care as an alternative to institutional care. "Home and Community-Based Service...waivers afford states the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities or intermediate care facilities for persons with mental retardation (ICF/MR). The HCBS waiver program recognizes that many individuals at risk of being placed in these facilities can be cared for in their own homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care. Initial waivers are approved by the Health Care Financing Administration (HCFA) to operate for three years. Waiver renewals are for periods of five years. The State of Oklahoma operates four Home and Community Based Services waivers (HCBS). Three waivers serve the mentally retarded and related conditions populace and one serves the frail elderly and adult disabled" (Oklahoma Health Care Authority 2002).

[4] "Habilitation Training Specialist (HTS) services include evaluation, assistance and training in self-care, daily living and prevocational skills. The HTS is the primary provider of residential or in-home supports, regardless of the person's living arrangement. The HTS also provides recreational and prevocational supports" (OKDHS-DDSD 2002).

Likewise, a 54-year-old woman described how her disability type and age keep her from receiving the health care coverage she needs:

> A program called D-Dent...helps people who have been disabled since birth & people over 65 that have low incomes but what about people who fit in the middle ground [—] disabled since 1991 & are only age 54 [?] Don't we count [?] We survive at poverty level, SSI + SSA + DHS aid to disabled...comes to 584.00 per month out of which I have to pay rent, utility bills, transportation, medicine, cleaning supplies [and] for groceries. I am allowed $10.00 [in] food stamps [and] after paying monthly bills I have little left for food & other necessities, much less pay [anywhere] from 500.00 to 1,000.00 for false teeth [—] so I don't eat quite as well as I would if I had teeth.

High medical costs can jeopardize financial security even among individuals covered by health insurance. One respondent wrote, "Fees charged by nursing homes and assisted living homes often exceed monthly payments from long term care insurance policies. This situation rapidly drains peoples' financial resources and forces them to rely on government support." Moreover, a 56-year-old woman with mobility impairment and a chronic illness wrote,

> Medicare pays very little of my total expenses. Last year, out-of-pocket medical expenses plus health insurance premiums were 25% of my total spending. So far this year they total 40%. .... I worry about getting the care I need. If I were to become as ill again as I was in the mid-1980's, I know I would not be able to get the same care now and would probably die.

Similarly, a 69-year-old male Medicare recipient with a hearing impairment wrote,

> My wife and I are fairly well educated, own our home and [are] able to take care of ourselves. Mostly, our problems are the high cost of insurance, medicine and doctor & dentist bills, also eye care.

A 51-year-old woman who received no governmental support described a problem typical of many middle-income individuals with disabilities:

> The main problem is lack of medical care, meds, etc. for people in the middle range of income. We get caught in the middle. We are 2 people with [a combined] income of $25,000 &...a lot is not [affordable].

Likewise, the mother of an 8-year-old daughter (visual impairment and mobility disability) suggested that Oklahoma "possibly institute a new state run insurance program for [middle] income people who make too much for regular Medicaid but can't afford regular insurance for handicapped children and people." A 44-year-old woman (neurological disability and chronic illness) expressed similar sentiments:

> There needs to be some kind of program to allow me to keep my Medicaid even as my husband's income increases. The rising cost of medical care would devastate us financially.

A 51-year-old man (hearing impairment and chronic illness) with a family income between $45,000 and $54,999 described his dilemma quite clearly:

> There is an impending cliff which is rapidly approaching for me, between COBRA and Medicare. After working full time for 26 years, I am learning everything from the ground-up. The financial upheaval is tremendous. I think I may die before everything is settled. I don't know how other people do it. Any financial tips?

Many respondents mentioned the obstacles they encountered while trying to find service providers willing to accept their government insurance. For example, the parent of a 20-year-old woman with a variety of disabilities (hearing, mobility, neurological, speech and mental retardation) wrote,

> When my daughter finally was able to get Medicaid, it was virtually impossible to find a doctor who would take Medicaid & was conveniently located. So we stayed with our Private Insurance [sic] for her so she can be seen when needed. The few Medicaid doctors are so booked, one has to wait weeks to get an appointment. What good is that when you're sick??

Another respondent, the parent of a 17-year-old girl with a hearing impairment, stated,

> It seems like only a few docs take Medicaid and...when you take [your children] to a doc they [refer] you to someone [else]. .... If you need to go to have a hearing aid [repaired], you have to go to your primary doc that [refers] you to the ear doc that [refers] you to the hearing aid doc that [refers] you to a hearing aid place, when all you needed to do is go [there] in the first place and it takes about 2 wks to get [approved] to even go. [A lot] of times it just gets frustrating. Like it's made to be so much trouble that they want you to give up and not use the services that are provided.

Oklahomans living in rural areas encounter special challenges in their efforts to find providers who will accept Medicaid. The parent of a 9-year-old girl with a variety of disabilities (hearing, speech, learning and mental retardation) living in Ottawa County wrote, "The process to get a Medicaid card was fairly simple but to find a provider in our area (rural) is very limited."

At the same time, providers themselves have been frustrated with many government health care programs, including SoonerCare.[5] For example, Dunbar and associates (1999) found that providers were concerned with SoonerCare's "auto enrollment" policy. One physician expressed annoyance with the

---

[5] SoonerCare is Oklahoma's managed health care program designed to serve Medicaid recipients in urban and rural areas. "It is, in fact, two programs - SoonerCare Plus and SoonerCare Choice. Comprehensive services, including behavioral health, are fully capitated to urban beneficiaries under SoonerCare Plus. Primary care office visits, case management, and diagnostic and ancillary services are provided to rural beneficiaries through a partially capitated arrangement under SoonerCare Choice. There are no cost-sharing requirements. In the SoonerCare Choice enrollment process, beneficiaries select a primary care physician (PCP) from the Choice Provider Network, rather than selecting an HMO (as under Plus). Beneficiaries are encouraged to select a PCP within 45 miles of their home and within 14 days of their application or they are autoassigned to a provider within 45 miles. If no provider is available within 45 miles, the beneficiary remains in the fee-for-services Medicaid program" (Dunbar, Sloane, Mueller 1999: 26-27). SoonerCare provides health insurance for children whose parents' income is up to 185% above the federal poverty level.

extent of information required for submitting claims. Moreover, "rural providers had little prior experience with managed care and were concerned that it would severely reduce their reimbursements" (Dunbar, Sloane, and Mueller 1999, 33).

One of the greatest problems associated with SoonerCare is that many eligible Oklahomans do not take advantage of the program. For example, between December 1, 1997, and September 30, 1998, Oklahoma enrolled 17,521 children in SoonerCare — just 43% of the eligible population (Dunbar, Sloane, and Mueller 1999). Possible explanations for this under-enrollment include a lack of awareness of the benefits of health insurance, a lack of understanding of the eligibility criteria (people may be eligible and not realize it), and the stigma sometimes associated with the receipt of government benefits.

Meanwhile, a significant number of individuals with disabilities feel that government health insurance provides substandard health care. For example, the parent of a 9-year-old boy with multiple disabilities (mobility, neurological, learning and mental retardation) opined, "People on Medicaid don't get the same equal treatment." Another parent of a child with a disability wrote, "Medicaid/Medicare [are] not adequate if [a] family needs to go see [a] specialist out-of-state. Parents seek out BEST physicians and many can't use them due to financial restraints [sic]."

At the same time, however, respondents expressed overwhelming support for SoonerStart, Oklahoma's early intervention programs for infants and toddlers with disabilities.[6] The parent of a one-year-old child (disability unspecified) wrote, "Sooner Start out of Lawton has been a big help to us" and the parent of a 3-year-old girl (speech impairment and mental retardation) wrote, "Programs such as Sooner Start are extremely beneficial for children with disabilities and their families that support those children. However, these programs need more funding in order to provide higher quality of support."

---

[6] SoonerStart is Oklahoma’s early intervention program designed to meet the needs of infants and toddlers with disabilities and developmental delays. Infants and toddlers through 36 months of age who have developmental delays or physical or mental conditions which will most likely cause a developmental delay (Down syndrome, cerebral palsy, fetal alcohol syndrome, etc.) are eligible for participation in this program. SoonerStart offers a variety of services including diagnostic and evaluation services; case management; family training; counseling; home visits; health services; nursing services; occupational, physical and speech-language therapy; and special instruction. SoonerStart services are provided in the child's regular environment — the child’s home, day care, or a relative’s home. SoonerStart is a joint effort of the Oklahoma Departments of Education, Health, Human Services, Mental Health and Substance Abuse Services, and the Commission on Children and Youth (Oklahoma Department of Human Services 2002).

The mother of a 2-year-old with Down Syndrome wrote,

> I am a 25-year-old mother of 3 children. My youngest, Ellen Sue Wright, is 2 yrs old and was born w/ Down Syndrome. I have been thankful for the SoonerStart Program. Since she was born they have been wonderful about helping all of us help Ellen accomplish goals that would have probably taken a lot longer w/out their help. Not to mention the fact that they come to our home for her therapy which helps tremendously!

Health Care Providers

Table 7
Responses:
Mental health and health care providers are sensitive to the needs of individuals with disabilities

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	0.5	2.2	1.0	0.4	0.0	0.5	0.0	0.0	1.1	0.7	1.0
% 2	0.5	0.9	1.0	1.8	0.7	1.0	0.5	0.0	0.5	0.7	1.1
% 3	2.1	5.8	3.5	3.5	0.0	2.5	2.1	1.1	3.8	3.4	4.1
% 4	13.9	15.6	11.8	15.5	9.4	16.9	11.9	12.7	11.9	11.6	13.3
% 5 (Very important)	82.9	75.6	82.7	78.8	89.9	79.1	85.5	86.2	82.7	83.7	80.4
Mean	4.8	4.6	4.7	4.7	4.9	4.7	4.8	4.9	4.7	4.8	4.7
n	187	225	313	283	138	201	193	181	185	147	982
% 1 (Not satisfied)	23.6	26.4	22.5	25.2	28.5	24.2	24.3	19.6	24.9	22.6	21.0
% 2	21.3	21.8	23.2	19.7	20.0	24.7	22.0	24.4	20.8	17.3	20.9
% 3	32.2	26.4	35.2	36.9	26.9	33.0	34.1	38.1	28.3	36.8	35.3
% 4	14.9	13.7	11.9	10.6	15.4	10.4	12.1	9.5	16.8	11.3	13.7
% 5 (Very satisfied)	8.0	11.7	7.2	7.7	9.2	7.7	7.5	8.3	9.2	12.0	9.2
Mean	2.6	2.6	2.6	2.6	2.6	2.5	2.6	2.6	2.6	2.7	2.7
n	174	197	293	274	130	182	173	168	173	133	892

More than 80% of respondents feel it is "very important" that "mental health and health care providers are sensitive to the needs of persons with disabilities." (See Table 7.) As might be expected, sensitive mental health care providers are especially important to respondents with psychological disabilities or mental retardation.

Many respondents expressed disappointment concerning the quality and commitment of mental health care professionals and 48 respondents, or 11% of those who provided written feedback, voiced concerns about health care providers in their written comments. A 59-year-old woman (psychological disability and other) summed up the sentiments of many respondents when she wrote,

> After being in the position of advocate for mentally ill peers (clients) I have experienced that for every concerned, helpful and caring [counselor], there are three that feel that their jobs are just that a job and as a result many of the wonderful [counselors] that have been in the mental

> health system have left after finding that they were running into problems with the administrative [personnel]. [Counselors] who would advocate for their clients were discriminated against.

Several respondents argued that many mental health care professionals did not seem to have the best interests of their clients at heart. For example, a 48-year-old woman (psychological disability and chronic illness) complained, "Mental Health providers...are so backward that they don't allow input into treatment plans by clients. They have cut back services to clients with mental illness to the bare bones [—] this is unacceptable." Similarly, a 49-year-old-man (mobility and psychological disabilities) wrote, "The mental health clinics are not there to talk and help heal; they just keep one on countless drugs, so the Vet is too doped up to care. And then, there are countless vets like myself where the medications are not monitored." Another respondent, a 31-year-old man with a chronic illness, wrote,

> Health care providers need to be more sensitive to people who are chronically ill and dying. ... Patients often feel as if they are a burden to the medical community because of insensitive staff and doctors. Need more one-on-one counseling available for those who aren't receptive to group counseling. Once again — none has ever been offered to me.

Some respondents did report positive experiences with the health care establishment, however, and several expressed gratitude for the services they had received from specific organizations that catered to their needs. For example, a 39-year-old woman with a variety of disabilities (hearing, chronic illness and other) wrote, "Carepoint [an organization that provides services for individuals who are HIV+ and/or have AIDS] is the best help that is out there that I have found, they are friendly, caring, and really go out of their way to help in any way they can. God Bless Carepoint." Another respondent, a 51-year-old woman with multiple disabilities (visual, mobility, neurological, and psychological), reported that "*some*" health care providers are caring and sensitive. Likewise, the parent of a 14-year-old boy with psychological and learning disabilities wrote, "the medical community is not always informed of state and federal laws although there has been a great willingness to learn. Providers are caring and sensitive."

Several respondents voiced a need for medical professionals to be more proactive in providing treatment for individuals with disabilities — especially by promoting early intervention for children with developmental disabilities. For instance, the parent of a 6-year-old boy with a hearing impairment wrote,

> If drs. do not refer for early intervention, it seems that children aren't serviced. My daughter (1st born) was 2 mo. premature. The private pediatrician in Edmond never voiced concerns. Since I was a new mom I relied on him to let me know if there were delays. On the other hand, when my son was born at University hospital and later (1 day) sent to Children's Hospital, we were bombarded with services and assessments. My son received Sooner Start & much testing to determine delays. As I compare baby books I can see that my daughter had far more delays than my hearing impaired...son. My daughter would have greatly benefited from early intervention. I feel that the private physician feared that I might be offended if he suggested Sooner Start.

Another respondent, a 58-year-old woman with a neurological disability, argued that physicians need to be better trained so that they can make accurate diagnoses of children with disabilities such as multiple sclerosis:

> Because of the reluctance and difficulty in giving a diagnosis of MS [multiple sclerosis], this is hard to evaluate. National standards of "normal range" of age when diagnosed [have] dropped, but there are many young teens living with symptoms that go on for years of bouncing from doctor to doctor. This is an education problem with our medical profession that needs to be addressed first and then we need to expand all programs of children & young adults.

Another respondent, the parent of a 22-year-old man with a variety of disabilities (visual, mobility, neurological, psychological and 'other'), asserted that medical professionals need to be better informed about substance use among individuals with disabilities: "My son suffered a traumatic brain injury 14 years ago & has had 17 major brain surgeries. .... What we were totally unprepared for was his involvement with marijuana while attending college. After 3 years of college he was a total dope-head and we never saw it coming! .... The health care professionals/providers need to be educated about drug use in individuals with disabilities."

Prescription Medication

Table 8
Responses:
Government health insurance programs (Medicare, Medicaid, etc.)
provide adequate coverage for prescription drugs

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	0.5	2.2	0.6	2.5	0.0	1.0	0.0	0.5	2.1	0.7	1.8
% 2	0.0	0.0	0.6	0.7	0.7	1.0	0.5	0.5	0.5	0.0	0.7
% 3	1.6	4.0	1.3	2.1	0.7	1.5	1.6	1.1	1.1	1.4	2.1
% 4	7.9	13.3	7.5	10.2	7.2	13.3	9.8	12.5	5.8	8.1	10.7
% 5 (Very important)	89.9	80.4	90.0	84.6	91.3	83.3	88.1	85.3	90.5	89.9	84.7
Mean	4.9	4.7	4.9	4.7	4.9	4.8	4.9	4.8	4.8	4.9	4.8
n	189	225	319	285	138	203	193	184	189	148	1037
% 1 (Not satisfied)	44.3	32.5	41.2	43.6	37.4	33.3	31.8	26.0	48.6	32.4	36.1
% 2	12.6	13.3	13.9	13.9	13.7	13.8	20.1	16.0	12.7	14.7	16.2
% 3	21.3	33.0	22.0	20.5	18.3	25.4	20.1	30.8	21.0	21.3	24.1
% 4	8.0	7.9	9.8	12.1	15.3	14.3	8.9	14.2	8.3	13.2	10.6
% 5 (Very satisfied)	13.8	13.3	13.2	9.9	15.3	13.2	19.0	13.0	9.4	18.4	13.0
Mean	2.3	2.6	2.4	2.3	2.6	2.6	2.6	2.7	2.2	2.7	2.5
n	174	203	296	273	131	189	179	169	181	136	953

Table 8 shows the extent to which respondents feel it is important that "government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for prescription drugs." Nearly 85% of respondents rated this need as "very important" while only 13% reported being "very satisfied" with the current situation. Individuals with chronic illnesses are the least satisfied, perhaps because they are more likely to rely on prescription medications. Those with neurological and visual disabilities also have especially high levels of dissatisfaction.

The need for a comprehensive prescription drug plan was one of the most frequently voiced medical concerns and 38 respondents, or 8% of those who provided written feedback, discussed prescription medication. In their comments, a number of respondents expressed disappointment with the fact that Medicaid covers only three prescription drugs per month. For many respondents, this restriction poses a serious financial hardship and sometimes threatens their physical well-being. For example, a 51-year-old woman with a variety of disabilities (visual, mobility, neurological and psychological) wrote,

> I'm on Medicare and Medicaid and can't get any other kind of insurance. My income is so low that I can't pay any other medical bills. I get only three [prescriptions] a month from Medicaid. It's left up to me which three are the most important for my life...If I could have gotten the proper medication in time I might have avoided some of the effects of a stroke. .... I am very bitter at how I've been treated, mostly by those in the medical field. There is little compassion shown by these people. But you get what you can pay for. If you can't pay — you get nothing.

Similarly, a 45-year-old woman with mobility and speech disabilities wrote,

> Medicaid only covers 3 prescriptions a month max. Many of the medications range b/w $100 — $200 each + if more than 3 prescriptions are needed — [you're] screwed. The income from SSI may only be $600 mo. + to spend $100 to $200 on drugs is hard to do. Therefore, sometimes you go w/o. This isn't good. This rule of 3 prescriptions a month should be changed.

A number of respondents complained about the high cost of prescription medication. One wrote, "Medicine is one of my most important [worries]. Cannot take all my medicine because I cannot afford them and be able to buy anything to eat." Similarly, a 46-year-old woman with a variety of disabilities (visual, hearing, neurological, psychological, and a chronic illness) wrote, "I am [on] 17 meds, several CANNOT be just stopped without putting my health and life in [jeopardy]. .... My monthly meds cost 3 times my monthly income!" Rising costs are of particular concern, as one 54-year-old woman with a hearing impairment noted:

> Medication goes up every year and doctors visits, compared to someone without disabilities, you have more payments of medical bills, and medication.

Routine Medical Care, Eye Care and Dental Care

Table 9
Responses:
Government health insurance programs (Medicare, Medicaid, etc.)
provide adequate coverage for routine medical care (doctor's visits, etc.)

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	0.0	1.8	0.7	1.5	0.7	1.5	0.5	0.6	1.1	0.7	1.5
% 2	0.0	0.9	0.7	1.1	0.0	1.5	0.5	0.6	0.0	0.0	0.6
% 3	1.7	3.6	1.0	1.9	2.2	2.0	0.5	1.1	2.2	3.4	2.5
% 4	8.4	12.9	6.3	8.2	5.2	12.1	8.0	10.1	9.5	6.9	9.3
% 5 (Very important)	89.9	80.9	91.4	87.3	91.8	82.9	90.4	87.7	87.2	89.0	86.1
Mean	4.9	4.7	4.9	4.8	4.9	4.7	4.9	4.8	4.8	4.8	4.8
n	178	225	303	268	134	199	187	179	179	145	1006
% 1 (Not satisfied)	30.7	32.2	33.5	36.7	39.6	32.1	36.4	31.0	40.9	31.9	31.0
% 2	13.6	15.4	13.0	16.5	14.9	14.7	16.3	16.7	17.7	15.9	17.2
% 3	25.6	22.4	24.4	21.6	17.9	24.2	19.0	24.7	19.3	26.1	24.9
% 4	15.3	15.4	16.1	15.1	13.4	17.9	13.6	17.2	11.0	14.5	14.7
% 5 (Very satisfied)	14.8	14.5	13.0	10.1	14.2	11.1	14.7	10.3	11.0	11.6	12.2
Mean	2.7	2.6	2.6	2.5	2.5	2.6	2.5	2.6	2.3	2.6	2.6
n	176	214	316	278	134	190	184	174	181	138	972

Many respondents voiced concerns about the need for health insurance to cover routine medical care. Of all the ODS survey questions, this one generated the highest proportion of "very important" ratings. At the same time, only a small minority of respondents are satisfied that this need is being met. (See Table 9.)

In their written comments, several respondents (17, or 4% of those who provided written comments) complained that government health insurance programs fail to provide comprehensive dental and eye care. For example, the personal caregiver of a 49-year-old man with a variety of disabilities (hearing, mobility and speech) wrote, "Need for Congress to consider dental health as a necessary inclusion in Medicare/Medicaid!!! Even if they just state 'cavities' or 'extractions.'" Similarly, a 57-year-old man with a chronic illness wrote, "Total dental care for people who can not afford it, including dentures!," and a 45-year-old man stated, "It is a crime that hardly any attention is given or can be received for regular dental maintenance. Much less restorative care or oral surgeries. I feel this needs to be looked at very seriously!!!"[7]

While routine eye and dental care is frequently not included in either governmental or private health insurance plans, individuals with disabilities have particular trouble paying out-of-pocket for these services. A 48-year-old woman with multiple disabilities (hearing, psychological, and learning) noted that "Medicare and Medicaid does not provide needed dental and vision restoration as well as preventive (dental & vision problems)." Similarly, a 64-year-old woman with a variety of disabilities (visual, hearing, mobility and chronic illness) wrote, "Why do physically handicapped people not have medical coverage for eyes or dental? This is quite a problem for most of us."

Medical Supplies

Table 10
Responses:
Government health insurance programs (Medicare, Medicaid, etc.)
provide adequate coverage for medical supplies (wheelchairs, hearing aids, etc.)

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	0.5	2.6	0.6	1.4	2.2	1.5	1.5	1.1	2.1	1.3	1.9
% 2	1.1	1.3	0.9	1.4	1.4	1.5	0.0	1.1	1.1	0.0	0.9
% 3	1.1	3.0	1.5	4.8	5.1	2.9	4.1	2.7	2.1	5.2	3.6
% 4	10.3	12.2	7.6	8.3	8.7	10.2	10.2	8.0	9.5	9.8	9.7
% 5 (Very important)	87.0	80.9	89.4	84.1	82.6	83.9	84.3	87.2	85.3	83.7	83.9
Mean	4.8	4.7	4.8	4.7	4.7	4.7	4.8	4.8	4.7	4.7	4.7
n	185	230	329	289	138	205	197	188	190	153	1044
% 1 (Not satisfied)	32.4	34.6	31.4	33.5	33.1	29.5	27.8	28.0	37.4	27.6	30.7
% 2	16.5	18.7	19.2	18.7	15.4	19.5	18.9	24.4	21.2	22.4	20.3
% 3	27.3	22.9	27.6	27.7	28.5	31.6	28.9	28.6	22.3	31.3	27.5
% 4	11.4	11.7	9.3	11.2	10.8	11.1	11.7	12.5	11.2	9.0	11.5
% 5 (Very satisfied)	12.5	12.1	12.5	9.0	12.3	8.4	12.8	6.5	7.8	9.7	10.0
Mean	2.6	2.5	2.5	2.4	2.5	2.5	2.6	2.5	2.3	2.5	2.5
n	176	214	312	278	130	190	180	168	179	134	957

---

[7] During the 1990s, the Oklahoma Medicaid program witnessed a significant decline in participation by dentists. "Between 1987 and 1998, the number of participating dentists declined from 1,021 to 171. The Oklahoma Dental Association said the problem is that dentists are paid only half of their traditional fee and they are not able to cover costs by treating enrollees. The Association also reported that HCFA would soon document the state as out of compliance with federal dental requirements for Medicaid children." (Dunbar, Sloane and Mueller 1999: vii).

The majority of respondents expressed dissatisfaction with Medicaid and Medicare coverage for medical supplies. (See Table 10.) For example, a 60-year-old respondent with a mobility impairment complained that government health insurance programs such as Medicare and Medicaid have "too many rules and regulations so some people can't get supplies they need." Likewise, the parent of a 14-year-old boy with a mobility impairment complained about "the time involved with getting new equipment [necessary] for his care." The parent of an 8-year-old girl with a visual impairment wrote,

> Hannah is a very bright & intelligent young girl. I have hope that she will be able to "live" in the community as normal as anybody else. I'm frustrated at the fact that despite paying taxes on the income my husband and I make, there are <u>limits</u> to funding for my daughter. We receive no support for equipment, computers, etc. These are <u>VERY</u> expensive and despite what our family makes, we cannot afford them. I was instructed by a lady at the Social Security Office to quit my job, then I could get funding, food stamps, etc. WHAT IS THIS WORLD COMING TO? No wonder so many people are getting help (assistance) that are just as able to work as I do. It is <u>NOT</u> <u>FAIR</u> that we choose to work and cannot get the things our daughter needs.

Several respondents complained that their insurance companies (both private and public) refused to cover specialized equipment altogether. For example, the parent of a 9-year-old boy (mobility and visual impairments) who received no governmental support wrote, "We...had to fight with insurance commissioner to get insurance to cover my son a wheelchair! Can't even get help making our small house accessible for him!!!" Another respondent, a 44-year-old woman with mobility and neurological disabilities wrote, "Another need is in the way of certain items such as roll-in shower chairs. Medicare and Medicaid will not cover such expenses but will pay for a stool to sit on in a bathtub. It is too hard for me or my aide to try to get me in a tub so I have to use the shower stall."

Another respondent, a 34-year-old female president of an organization that serves individuals with disabilities (who herself has a mobility impairment), wrote,

> My greatest concern is that disabled, productive & <u>yet functional</u>, individuals are not provided with needed funding via healthcare coverage for technology such as prostheses, wheelchairs, seating systems, and communication devices. These items are often looked at like "luxury" items, yet they are necessary to maintain a <u>productive</u> lifestyle.

Some respondents voiced a need for financial help with specialized medical equipment, although they did not necessarily want government-sponsored health insurance. For example, the mother of two children who had disabilities wrote,

> I'm a mother of 2 Waardenburg[8] children with hearing losses. Allison who I answered the questionnaire on is deaf. She gains...more with her hearing aids, but she is in need of more. We would like to get her digital, but they're 6,000.00 beginning. We can't afford that. My son was just diagnosed with the syndrome & a possible hearing loss[;] he is 2 yrs. old. The law that states insurance provide money for hearing aids we are the only exception. So it would be out of pocket. If you know of a way we can get hearing aid besides SSI or medical card please let me know.

Many ODS respondents also voiced concerns about the exorbitant cost of products specifically marketed to individuals with disabilities. For example, a 51-year-old woman with a variety of disabilities (visual, mobility, neurological, and psychological), wrote, "It's terrible what suppliers charge for their services or products" and a 45-year-old woman (mobility and neurological disabilities) wrote, "Prices are entirely [too] expensive for needed items of the disabled. Got to have them, so have to pay it. We are taken advantage of — PERIOD!" Similarly, the parent of a 12-year-old with a variety of disabilities (mobility, neurological, speech, mental retardation, chronic illness and other) reported that "Case managers do not look out for the child when they hand waiver dollars over to providers who basically steal and over-charge. $8.49 for 1 tub baby wipes, <u>unacceptable</u>! Diapers $87.77 per box. Why does this go on?" The parent of a 10-year-old boy with a speech impairment and mental retardation wrote:

> Funds & resources are limited. If you need something for your child, the parent must come up with "creative ways" of providing that service, most often at your own expense. Many people [with] disabilities simply fall through the cracks.

One respondent suggested that some of the problems of health care financing could be overcome if Medicaid and Medicare relied less heavily on rentals:

> Medicaid/Medicare — From my viewpoint I see them [Medicaid/Medicare] wasting tons of $$ on rental equipment. [It] would cost less to buy [supplies]...and instead of over paying by long-term rental you'd have more $$'s to use elsewhere.

Another respondent, a 34-year-old woman with a psychological disability, complained that both supplies and disability testing are overpriced:

> Affordable disabilities testing should be available to everyone...In the community, I would have to pay $400-$600, which I cannot afford.

---

[8] Waardenburg syndrome (WS) is an inherited disorder often characterized by varying degrees of hearing loss and changes in skin and hair pigmentation. The syndrome got its name from a Dutch eye doctor named Petrus Johannes Waardenburg who first noticed that people with differently colored eyes often had a hearing impairment (National Institute on Deafness and Other Communication Disorders 1999).

Respondents did offer some positive comment regarding health care coverage for supplies. For example, a 66-year-old man with a mobility impairment wrote "Medicare has been great. ... Medicare helped me get a motorized wheelchair & I am in it about 16 to 18 hrs. a day." The same respondent acknowledged that his private health insurance (sponsored by his former place of employment) may have contributed to his success in procuring needed equipment and services.

Community-Based Services and Attendant Care

Table 11
Responses:
There is adequate support for independent living
for disabled individuals who wish to avoid institutionalization

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.1	5.4	2.2	1.8	1.5	2.6	2.6	1.1	1.6	2.8	3.6
% 2	0.0	0.0	0.3	0.7	0.0	0.5	0.5	0.6	1.1	0.0	0.6
% 3	3.3	9.5	2.6	4.7	3.7	4.1	3.7	5.0	5.9	3.5	5.0
% 4	12.1	16.2	10.5	9.3	9.6	11.8	10.1	9.4	12.3	9.2	12.1
% 5 (Very important)	83.5	68.9	84.3	83.5	85.2	81.0	83.1	84.0	79.1	84.5	78.6
Mean	4.8	4.4	4.7	4.7	4.8	4.7	4.7	4.7	4.7	4.7	4.6
n	182	222	313	279	135	195	189	181	187	142	1014
% 1 (Not satisfied)	30.5	28.5	33.8	38.0	37.7	32.6	40.5	30.9	33.5	39.0	30.5
% 2	23.2	19.7	23.3	23.3	24.6	25.3	19.6	23.6	24.9	21.1	22.4
% 3	26.8	34.7	23.7	22.2	19.7	27.5	23.2	27.9	25.4	23.6	29.5
% 4	8.5	6.7	6.6	6.0	6.6	7.3	5.4	7.3	6.4	4.9	7.6
% 5 (Very satisfied)	11.0	10.4	12.5	10.5	11.5	7.3	11.3	10.3	9.8	11.4	10.1
Mean	2.5	2.5	2.4	2.3	2.3	2.3	2.3	2.4	2.3	2.3	2.4
n	164	193	287	266	122	178	168	165	173	123	903

Table 11 shows that respondents rank support for independent living as less important than health care coverage. A large majority characterize it as "very important," however, and less than 18% are satisfied with the current situation. Individuals with hearing impairments are less likely than others to rate this need as very important, perhaps because they are at low risk of institutionalization. In their written comments, many respondents — particularly those with developmental disabilities, dementia, or chronic physical disabilities — stressed the importance of independent living and the need for greater government support of community-based services and attendant care.[9] Moreover, 74 respondents (or 16.3% of those who provided written comments) discussed the need for community-based services and attendant care. The personal caregiver of a 19-year-old male nursing home resident with a neurological disability summarized the sentiments of many respondents when he wrote,

> #1 need is for adults with physical disabilities who are not mentally retarded to have the <u>same services</u> and <u>rights</u> to <u>live in the community</u> as those who are mentally retarded. This is <u>not</u> happening. Currently a class action lawsuit against DDSD [Developmental Disabilities Services Division] and the state of OK is being planned that will cost millions (Remember Hissom?)[10] Too bad that money can't be spent on services!!

The desire to avoid institutionalization was voiced by a number of respondents. The parent of a 13-year-old boy with a multiple disabilities (visual, mobility, speech and mental retardation) emphasized the need to "[provide] families the support needed to have a child w/ significant disabilities live in the home if the parents want that." Similarly, a 62-year-old woman with a variety of disabilities (visual, hearing, mobility, and neurological) wrote that individuals with disabilities need help with "upkeep" and "maintenance to be able to live independently in our homes." A couple in their seventies, both with mobility impairments, wrote,

> Husband paraplegia, Wife polio. Both confined to wheelchairs, 58 yrs and 48 respectively. Desire to live in home rather than face nursing home care. Financial and physical aid will be necessary within a few years.

For some respondents, the lack of adequate support for in-home care eventually led to institutionalization.

---

9. In July 1999, the Supreme Court issued the Olmstead v. L. C. decision. "The Court's decision in that case clearly challenges Federal, state, and local governments to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community-based services. The Olmstead decision interpreted Title II of the Americans with Disabilities Act (ADA) and its implementing regulation, requiring states to administer their services, programs, and activities 'in the most integrated setting appropriate to the needs of qualified individuals with disabilities.'" In practice, this has meant that many services formerly provided on an institutional basis are now carried out in clients' homes (Centers for Medicare and Medicaid Services 2002).

10. The 1987 Homeward Bound, Inc., versus Hissom Memorial decision compelled the state to create community-based alternatives to institutional placements. The resulting court order also required the closure of the Hissom Memorial Center.

For example, one woman wrote,

> My mother-in-law has to be admitted to a rest home because there are no home nursing services available. To enable her medication supervision, the rest home was our only possible alternative. The dementia has robbed us of a wonderful person, and the system has totally removed her from our lives. However, we are very grateful for the ICF [Intermediate Care Facility] that another relative lives in at the present time.[11] Even though her limited mental [acuity] has greatly diminished in the last few years, she has received adequate & loving care for the last 26 years.

A number of respondents stated their concerns about the level of support for community-based living for individuals with developmental disabilities. For example, the mother of a 22-year-old woman with a variety of disabilities (visual, mobility, neurological, psychological, speech, mental retardation, and autism) wrote, "Autistic [people's] needs are not being met in Oklahoma. I am working 24 hr. days 7 days a week. .... I am applying for hourly services 24 hr a day which Rebecca [autistic daughter] needs, it has been turned down by D.H.S." Likewise, the parent of a 20-year-old woman with a variety of disabilities (hearing, mobility, neurological, speech and mental retardation) wrote,

> System for HTS [Habilitation Therapy Specialist] is way under-funded — In Home Support Waiver is a [farce]! It took a year to find an agency that would serve us, then had to change agencies, & then took another year to find a person willing to work part-time flexible hours as families need & not strict shift-work. The more disabled one is, the fewer services & fewer opportunities & much less accessibility.

Respondents with physical disabilities also voiced concerns about inadequate support for in-home care. For example, a 44-year-old woman with mobility and neurological disabilities wrote, "I need help at all times transferring wheelchair to commode and I have a provider for 3 hours each day to help me out of bed, bathe, housework, etc. The rest of the day I have to depend on whomever is around." Similarly, a 69-year-old man with a mobility impairment wrote,

> I need home health care, I can't get that...I'm 70 yrs & been a quadriplegic since 9-3-1973 28 yrs. I never got any help inside any house. No one helps disabled quadriplegics! No one. Yes I'm mad just because no one cares — Medicare is crooked.

---

11. In 1971, institutional services for children and adults with mental retardation were greatly influenced by the establishment of Medicaid reimbursement to facilities meeting the standard for care as Intermediate Care Facilities for the Mentally Retarded (ICF/MR). This standard specifies staffing levels, the development of treatment plans, the provision of active treatment, the use of medications and the maintenance of an appropriate physical environment. State-operated facilities, as well as many private nursing homes, choose to become licensed as ICF/MRs in order to qualify for Medicaid reimbursement (OKDHS-DDSD 2000a).

Another respondent, a 30-year-old woman with a variety of disabilities (mobility, neurological, chronic illness and other), echoed this concern:

> My biggest gripe is I have Medicare, but to receive nursing I must be homebound. I am no way homebound, but I do need at times [aides], but cannot afford to pay out of pocket.

It is noteworthy that one respondent, a 66-year-old man with a mobility impairment, had good things to say about the assistance provided by ElderCare[12] He stated that the service "is a big help" in getting chores done around the house.

Table 12
Responses:
Good quality attendant care is available

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.6	5.4	2.5	1.4	2.2	2.0	3.6	2.2	2.1	0.7	3.4
% 2	0.0	1.4	0.3	1.4	1.5	0.0	0.0	0.0	1.6	2.0	1.2
% 3	7.7	6.8	4.4	6.6	10.2	8.2	8.3	9.3	6.4	4.1	7.7
% 4	12.6	19.5	13.3	16.4	12.4	15.8	13.0	9.8	16.6	10.8	13.8
% 5 (Very important)	78.0	67.0	79.4	74.1	73.7	74.0	75.0	78.7	73.3	82.4	73.9
Mean	4.7	4.4	4.7	4.6	4.5	4.6	4.6	4.6	4.6	4.7	4.5
n	182	221	316	286	137	196	192	183	187	148	1017
% 1 (Not satisfied)	25.7	21.1	27.7	26.4	25.8	27.4	32.7	28.9	27.8	25.9	22.4
% 2	25.1	26.3	30.1	28.3	31.5	29.1	26.2	27.7	20.1	17.8	24.9
% 3	29.9	34.7	26.7	29.4	27.4	30.9	27.4	31.9	34.3	33.3	34.9
% 4	8.4	7.9	9.2	10.9	9.7	8.0	6.5	6.0	10.7	9.6	9.9
% 5 (Very satisfied)	10.8	10.0	6.2	4.9	5.6	4.6	7.1	5.4	7.1	13.3	8.0
Mean	2.5	2.6	2.4	2.4	2.4	2.3	2.3	2.3	2.5	2.7	2.6
n	167	190	292	265	124	175	168	166	169	135	901

Many respondents complained about the *quality* of in-home care. (Table 12 shows the importance of high-quality attendant care, and the extent of dissatisfaction with the services currently available.)

---

[12] "Eldercare is a comprehensive, in-home community-based care system which introduces elderly clients to health and social services in their community, and then coordinates and arranges needed services to be delivered. The program allows the frail, at-risk elderly to continue independent living with the assistance of services coordinated through an Eldercare manager. The program stimulates communities, groups and individuals to develop creative and cost-effective resources for the elderly, decrease fragmentation of services, and integrate community resources into a productive network which promotes a high quality lifestyle for the elderly and avoids or delays placement in long-term care facilities. In some counties, this program is not based in the county health department; however, local health department staff are familiar with the program and its provider, and make appropriate contacts when needed" (Oklahoma State Department of Health 2002).

Because in-home caregivers are often paid low wages by both public and private insurance plans, many respondents have great difficulty finding and retaining qualified help. For example, the close relative of a 52-year-old woman with mental retardation wrote, "The care givers only get paid $6.00 or $6.50 depending + mileage, so getting someone to stay interested is extremely hard." Similarly, the parent of a 12-year-old girl with several disabilities (mobility, neurological, speech, mental retardation and chronic illness), wrote, "Attendant does not show up." The need for "better training for attendants such as home health care [aides]" was also noted by many respondents, including a 54-year-old woman with a chronic illness.

Many of the complaints about in-home care were directed specifically at the Habilitation Training Specialist [HTS] program. For example, the parent of a 9-year-old girl with a variety of disabilities (mobility, neurological, speech, learning, mental retardation and chronic illness), wrote, "Thru Dev. Dis. [Services] HTS [Habilitation Training Specialist] services are available. The agencies are horrible, the people are inadequate & the cost is a crime. Out of the $12 they receive per hour they only pay HTS $6-8/hr. which means they pocket the rest. This is through the waiver program." The parent of a 26-year-old woman with several disabilities (neurological, psychological, learning and other) expressed similar sentiments:

> We have tried for 22 years to find someone who qualifies to teach independence. But most everyone has no training, not reliable, responsible or honest. She [my daughter] has a social life but most HTS want to take her out on the street. She needs to learn how to maintain a home <u>first</u>! [Agencies] do not even do a <u>back ground</u> [sic] check + that is mighty frightening.

Another respondent, the parent of two children with disabilities (one with a speech impairment and the other with a seizure disorder), wrote, "There isn't enough social activities available & the H.T.S.'s don't want to take them to those available." Similarly, the mother of a 19-year-old woman with Down Syndrome complained,

> The whole system in Okla. is a joke! It took us <u>8 months</u> to receive services for her [daughter with Down Syndrome]. I was treated horribly! And still <u>we</u> had to provide an HTS because nobody was qualified, available, or willing to work with her. All we needed was transportation from Choctaw to Moore. We currently have a family friend working w/ her, but this is <u>not</u> the program we wanted — nor is it the best for her; but at least it is something...

A few respondents complained that delays in payment for personal care assistants were a problem. For example, one respondent who served as a personal caregiver complained, "I feel personal care attendants are not paid as much as habilitation [aides]...Also some of us have a great deal of trouble getting our pay checks in a reasonable length of time...I think we should get our pay within two weeks — not 3-4 weeks. I'm working under a waiver program." Similarly, a 51-year-old woman complained that her personal care assistant was not being paid in a timely manner. "I filed (wrote a letter of [complaint]) to the State of

Oklahoma Personal Assistant Program. I am one of a few in Oklahoma that was grandfathered into the waiver program. I've had the same personal assistant (live-in) for over 18 years. Her pay is low as it is but they have failed to get what little money she is due on time. Sometimes they have delayed as long as a month."

Respite Care

Table 13
Responses:
Temporary care (respite and/or attendant care) is available to ease the burden on regular caregivers

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	2.8	5.8	4.1	2.1	1.5	3.4	3.6	1.6	2.6	2.7	4.3
% 2	0.6	2.2	0.6	2.1	2.2	0.5	0.5	1.1	0.0	1.3	1.5
% 3	7.2	9.0	7.6	8.5	9.5	7.4	5.7	5.5	12.0	6.0	8.3
% 4	11.0	17.9	14.2	18.5	12.4	14.8	10.3	10.4	14.7	13.4	15.8
% 5 (Very important)	78.5	65.0	73.5	68.7	74.5	73.9	79.9	81.3	70.7	76.5	70.2
Mean	4.6	4.3	4.5	4.5	4.6	4.6	4.6	4.7	4.5	4.6	4.5
n	181	223	317	281	137	203	194	182	191	149	1027
% 1 (Not satisfied)	33.1	28.4	34.2	33.8	38.7	41.3	44.6	42.7	24.7	31.5	28.5
% 2	24.3	22.6	27.8	24.1	20.2	20.7	21.5	19.9	24.1	19.7	23.0
% 3	24.3	34.2	25.8	31.2	28.2	24.0	18.1	25.7	35.6	35.4	33.7
% 4	8.9	5.3	6.1	5.3	6.5	8.9	5.6	7.0	8.0	5.5	7.9
% 5 (Very satisfied)	9.5	9.5	6.1	5.6	6.5	5.0	10.2	4.7	7.5	7.9	6.9
Mean	2.4	2.4	2.2	2.2	2.2	2.2	2.2	2.1	2.5	2.4	2.4
n	169	190	295	266	124	179	177	171	174	127	909

The importance of temporary (respite) care can be seen in Table 13. The need for this kind of assistance was most commonly mentioned by relatives and caregivers who completed the survey on behalf of someone with a disability (15 respondents made specific reference to the need for respite care in their written comments). Their written comments highlight many of the emotional and financial burdens that caregivers assume, especially when dealing with chronic illness. For example, the parent of a 4-year-old boy with variety of disabilities (visual, hearing, mobility, neurological, speech, learning, and chronic illness) wrote,

> [My] son needs nursing assistance because he is on a ventilator — there is no day care that accepts him. We are only allowed so many hours a day and it is [dependent] on how much is 'medically necessary.' There is a problem here because if my son is only medically needing 4 hours a day then I can only leave 4 hours a day. This does not provide enough hours in a day for me to work. This is especially important for single parents who [do] not have any financial or personal assistance from the other parent. I see it as medically necessary for more assistance to earn more money to pay rent, car payment, diapers, medicines, etc. Without money I cannot support him. And since he cannot attend day care — we are very

> limited in everything we do. Some days I feel like I am going to have a nervous breakdown because the only time I leave my house is for work which is stressful and then I go home and never get out to go do normal things — go out w/ friends or see a movie.

Another parent described the constant struggle of caring for a young daughter with a major disability:

> My daughter was born with cerebral palsy. She passed away in 1996. I completed this form based on what I (we?) as parents experienced during her brief life. What do I really believe is needed: 1) marital counseling for parents of disabled children, particularly those with a severe disability; 2) respite care — caregivers cannot be expected to function adequately if they never get a break. Our respite care came only when our daughter was experiencing one of her many hospitalizations. 3) Financial assistance, adequate support services, training, advocacy are all also very important. The two biggest aids to us were The Little Light House in Tulsa (private, non-profit) and state programs such as Sooner Start. Federal government programs were completely unresponsive to our needs. Our insurance company (Pacificare) provided well for doctor visits, medications, & hospitalizations. Getting them to provide adequate nursing care was extremely difficult, though not impossible. My daughter required constant care. She was fed via a g-tube and was trached. Because we never got any emotional and only limited physical relief from her care, my marriage suffered greatly.

The notion that inadequate respite care threatened family stability was also voiced by the close relative of a 24-year-old woman with multiple disabilities (visual, mobility, neurological, psychological, speech, learning, mental retardation, and chronic illness): "Family and caregivers need respite help so that they can stay together as a family."

The parent of a 9-year-old girl with a variety of disabilities (mobility, neurological, speech, learning, mental retardation and chronic illness) expressed a need for more comprehensive respite care:

> There needs to be more respite opportunities for [families] & caregivers. At this time only 3-4 <u>churches</u> in the Tulsa community provide it & it's on Fri. [evenings] & at the same time. It would be very helpful if there were Day Care facilities that would be funded so that caregivers didn't have to pay.

Similarly, the parent of a 33-year-old man with mental retardation wrote, "There needs to be camps in summer for [mentally] retarded children and more so for adults. All I ever hear about are for the CP [Cerebral Palsy], MD [Muscular Dystrophy] or terminally ill. Also a place for them to stay to give the caregiver a weekend or even a week vacation so the caregiver is not tied down all the time." The benefits of respite care were most clearly described by the mother of a 50-year-old man with a variety of disabilities (visual, mobility, neurological, speech, and learning). She wrote, "I just started getting respite care for help in taking care of cleaning and care for David. It has [helped] <u>much!</u> <u>much!</u>"

Long-term Residential Facilities

Table 14
Responses:
Group homes for mentally and physically disabled children are available in your community

	Rural	Suburban	Urban	Oklahoma City County	Tulsa County	All Other Counties	Total
% 1 (Not important)	4.6	6.5	6.8	7.2	11.6	4.6	6.1
% 2	2.0	2.4	1.1	1.7	2.7	1.9	1.9
% 3	11.5	12.8	10.3	13.8	9.8	11.4	11.6
% 4	14.1	16.1	14.4	13.8	15.2	15.0	15.7
% 5 (Very important)	67.8	62.2	67.3	63.5	60.7	67.0	64.5
Mean	4.4	4.3	4.3	4.2	4.1	4.4	4.3
n	304	336	263	181	112	412	987
% 1 (Not satisfied)	32.9	23.3	26.3	26.0	22.8	28.9	27.3
% 2	23.1	23.7	19.8	18.0	20.7	21.5	22.1
% 3	31.4	35.9	40.9	42.7	43.5	32.4	35.7
% 4	6.9	10.1	8.2	8.7	5.4	11.1	8.6
% 5 (Very satisfied)	5.8	7.0	4.7	4.7	7.6	6.1	6.3
Mean	2.3	2.5	2.5	2.5	2.5	2.4	2.4
n	277	287	232	150	92	377	275

Quite a few respondents are dissatisfied with the availability of group homes and other long-term residential facilities for children. (See Table 14.) Moreover, 30 respondents (or 6.6% of those who provided written comments) expressed concerns about residential facilities. Respondents living in Oklahoma County or Tulsa County are less likely to see this as a problem, while those living in rural areas are especially likely to be dissatisfied. For example, a personal caregiver wrote,

> I live in McAlester where there are no [facilities] for children with mental disabilities. No group home or hospital. No inpatient services. They are referred to Ada, Tulsa, or somewhere far off. We have a hospital for adults and day centers but none for children.

Similarly, the parent of a 10-year-old child with a variety of disabilities (visual, mobility, speech, and mental retardation) living in Del City wrote, "Group homes for children with disabilities that are young (<16) are not at all available in our community. Most group homes have [large] aggressive young adults."

Several respondents expressed a need for more residential living facilities for older adolescents and adults with disabilities. For example, the close relative of an 86-year-old man with multiple disabilities (hearing, mobility, and chronic illness) wrote, "Need increased numbers of private homes for elderly disabled — group homes." A respondent in Oklahoma County wrote next to the survey question, "Adults!" and the parent of a 17-year-old male with a variety of disabilities (neurological, psychological, and learning), wrote, "Need more 'group homes' or assisted living for the mentally ill, autistic, etc. — not just physically or mentally handicapped."

The ODS respondents are also concerned about the quality of services delivered at group and nursing homes throughout the state.[13] The problems most often mentioned are that (1) staff neglect and mistreat clients; (2) staff are lacking in number and/or inadequately trained; and (3) staff financially exploit clients. The close relative of a 60-year-old woman with a variety of disabilities (visual, hearing, speech and mental retardation) summed up the sentiments of many respondents when she wrote, "For the most part group homes and facilities for mentally handicapped are very bad! Many are filthy and run by people that do not care for the residents."

Several instances of abuse at residential living facilities were documented in respondents' comments. The parent of a 53-year-old man with a multitude of disabilities (visual, hearing, mobility, neurological, speech and mental retardation) wrote:

> We need lots more done. We are one of the lowest paid states for people with disabilities. We have been thru a lot with my son. He was beaten at a home and no law enforcement wanted to do anything. They don't feel disabled are worth anything. The judges also let the abusers off on probation, but [their] name isn't put on record so they do it again. All facilities should be non-profit or only 10 to 12% profit. The owners take up to 30% of what the government pays for peoples' care & our family members go without. Enid and [Paul's] Valley should be shut down.

Similarly, the parent of a 24-year-old woman with mental retardation living in Oklahoma County wrote,

> Available group homes provide inadequate level of care due to staffing. Quality of staff is lacking — staff yell/curse at clients. Staff do not provide adequate transportation. Staff do not provide timely transportation. Staff does not allow friends to spend night at group home in [resident's] room.

The parent of a 29-year-old with mental retardation described how his/her daughter had been mistreated as a residential facility in Okarche:

> Finding a good place for Barbara [daughter] to live on her own is very important. She had a very very bad experience at the Center for Family Love in [Okarche]. (They should change their name since that is not what goes on there.) Now she is very afraid to try someplace else — good living [arrangements] are very important to both us and her.

---

[13] "The Office of Client Advocacy (OCA) provides a variety of protection and advocacy services for DHS clients...Their mission is to provide an independent, proactive voice for all clients to ensure client safety and fair, honest and professional service delivery. The Office of Client Advocacy's (OCA) investigation unit promotes the protection of Oklahoma's citizens by investigating allegations of abuse, neglect, mistreatment, and financial exploitation with regard to all children living outside their homes (except for foster home placements and children living with relatives) and certain individuals with developmental disabilities, including those who reside in DHS-operated facilities. During the 1999 fiscal year, OCA received 2,037 referrals for potential investigation. Many were addressed informally, while 770 resulted in investigations. Approximately one-third of OCA's investigations result in a finding that abuse, neglect, mistreatment, or exploitation have occurred" (Oklahoma Department of Human Services 1999).

Another respondent described how her son had been sexually abused at a residential living facility, and several more reported that their close relatives had been financially exploited. The mother of a son with a mental retardation wrote,

> First I placed my son in Choctaw living Center where things initially went well. Then due to the lawsuit, Choctaw was forced to take clients who had behaviors much worse and different than when he was 1st placed there. My son was sexually abused on at least two [occasions] in Choctaw. I then moved him to the Nova Center in Edmond where he was taken well care of for a few years. Nova did not seem to be able to hire or retain a...QMRP [Qualified Mental Retardation Professional] — they had at least eight in as many years and there were long periods when there was no QMRP and the nurse or don had to do double duty — as well as other under-trained staff. .... He [son] was sexually abused both by clients and at least one staff member. My son began to become reclusive and quiet and told me over the phone that he was so confused and lonely that he only wanted to go to his room and cry. .... His money was also mishandled and probably stolen but I can't prove it. I asked for 3 years for some sort of accounting but never received any.

This same respondent complained that the Nova Center lacked sanitary living conditions: "As I removed more & more endless, useless junk, bugs began to crawl out of everywhere. I found ancient food items and unopened mail up to 2 years old, some from social security dept. Clients may have 'rights,' but using that excuse with M.R. clients is jeopardizing their safety." Similarly, the parent of a 33-year-old with a neurological disability wrote, "Joe Walters is now at (Norman) Griffin Memorial Hosp. He is a victim of crime (head injury). He was at Vinita for (10) yrs. He was almost totally healed...but the staff at Eastern stole his...savings of $5,000."

Even when physical abuse and financial exploitation are not an issue, few respondents receive adequate care at residential living facilities. The parent of a 23-year-old woman with mental retardation and a hearing impairment reported, "My daughter is in a group home [in Oklahoma County]. There needs to be more activities for disabled people to do. She gets very bored then her behavior becomes violent." Another woman complained that unsatisfactory care at a group home compelled her to assume caregiving responsibilities for her 22-year-old autistic daughter:

> My daughter is low functioning autism. I am her [companion]. She lives at home with me [and] shares expenses for the home. I became her [companion] mainly because staff could not handle her and [there] was constant staff turnover. Her disability is puzzling, and most staff cannot work with this problem. I know her so well (has lived at home most of her life) so she is not difficult for me.

Several respondents took the opportunity to voice concerns about the services provided at nursing homes throughout the state. For example, the parent of a 30-year-old woman who was living in a nursing home in Cleveland County wrote, "If [you're] on [Medicaid] there is no real help for you! I'm [grateful] if she gets her diapers changed. Nursing home victims are all disabled!"

Perhaps as a result of these stories of neglect and abuse, many respondents expressed considerable anxiety about the prospect of placing their loved ones in a group or nursing home. The parent of 30-year-woman with multiple disabilities (neurological, speech, and mental retardation) wrote:

> We could not with a clear conscience place Julie in any institution, group home, etc. We visited — example look at the mess at Cottonwood[14] in Yukon...I see many adult disabled persons still living at home with their parents because...the parents do not have the financial resources to set them up in independent living — nor, do they want the worry & concern that goes with letting the disabled person out of their sight. But, my question to you is what happens to the disabled adult when those parents can't take care of them due to age or death?

The Bureaucracy of Obtaining Government Benefits

Dozens of ODS respondents have been caught up in the bureaucracy of obtaining government benefits (42 respondents complained about this problem in their written comments). Long waiting periods, rude and uninformed employees, and complicated paperwork seem to be the norm. In fact, many of the respondents' written comments give a sense that any effort to obtain government support will involve a struggle. For example, the parent of a 24-year-old male SSDI recipient with a neurological impairment wrote:

> The state is overworked, where we meet and plan out [my son's] goals they are never [enforced], thus never met. I cannot even fathom parents that are separated or do not have the financial or mental capability and strength to fight to get the services they deserve.

The mother of a 21-year-old woman with a variety of disabilities (hearing, speech, learning and mental retardation) also expressed considerable frustration with the system.

> Looking back over the last 21 years, Oklahoma has <u>not</u> improved <u>any</u> services for their disabled. 90% of all agencies & schools receive the funding necessary, but do only the minimal service(s) to keep within the legal limits. No extra effort is made. Parents & guardians have to fight the system, the people (employees) and the red tape in an attempt to get what is needed for their child — all of their life! <u>It's a mess</u>! There are very few people in these professions/careers that truly care about their clients' needs as an individual.

Many respondents have faced impossible demands from state and federal agencies. For example, the parent of an 11-year-old hearing-impaired boy in Oklahoma County wrote,

> SSI has many problems and the amount of financial compensation does <u>NOT</u> offset the callous treatment by this department. Their requirements are ridiculous. For instance, I received a denial letter (after we had been receiving SSI for either months for the <u>very same</u>

---

[14] In July of 2001, the Oklahoma State Department of Health (OSDH) announced that it had been unable to find an acceptable temporary manager to provide the oversight necessary to protect the health, safety and welfare of the residents of Cottonwood Manor in Yukon. As a result, OSDH closed the home down and all residents of the facility were relocated.

> reason we were almost initially denied) requiring that I return a form within 10 days yet they did not send the required form with the letter. The person said I should receive the form in 7-10 working days. I explained the letter I received but it seemed not to be any concern for her. I received the form, filled it in, mailed it in promptly and still benefits were stopped. .... I am still angry about this. At the initial appointment I had to provide a copy of their SSI brochure with the IRA rules for parents highlighted. They didn't even know their own rules and then eight months later FORGOT their rule and denied us. I think they've designed [it] so people are so frustrated that they don't bother with SSI again.

Another respondent, the parent of an 18-year-old SSI recipient with mental retardation in Tulsa County, reported that "Dealing with SSI or the State has been a nightmare. They won't return calls and everyone tells you something different." Likewise, the parent of a 9-year-old child with a variety of disabilities (mobility, neurological, speech, learning, mental retardation and chronic illness) wrote,

> The paperwork & time frames make it difficult and most parents just give up [trying to get benefits]. We are too busy & exhausted to fight these battles all the time. And, when the children need the meds, or equipment or services they don't need to be put off for 2-4 months.

Quite a few respondents are angry at the system for requiring them to jump through so many hoops — many of which seemed absurd — in order to obtain benefits. For example, the mother of a 17-year-old son with cerebral palsy (CP) wrote,

> I'm tired of having to prove every year that my son hasn't woke-up one day...cured of his CP! Well hello I'd love for it to happen, but I'm still waiting and no he doesn't receive SSI-DCP [Supplemental Security Income Disabled Children's Program]!"[15]

---

[15] The Supplemental Security Income-Disabled Children's Program (SSI-DCP) is established under Section 1615 of the Social Security Act. "This provides for the referral by the Social Security Administration (SSA) for Supplemental Security Income (SSI) recipient children who are under 18 years of age to a designated state agency which provides social services" (Oklahoma Department of Human Services 2002: Title 340, Chapter 70, Subchapter 8-1). Any child aged 18 years or younger is eligible if he or she receives a Supplemental Security Income (SSI) payment. SSA establishes financial and medical eligibility for the SSI disability payment. Services available locally or through SSI-DCP funding include child care, equipment, diapers, formula, developmental aides, and professional services.

Similarly, the parent of a one-year-old girl with mental retardation described how she had been asked to supply a "psychological evaluation" for her child:

> Having a child with a disability is very frustrating. From the way you are first told of the disability to the waiting for information and referrals. I applied for SS in June of 2000 when my daughter was born. I was told that I made too much (over the telephone). I never followed up after that. A year later I reapplied only to find out that my income which they said was too high before was my gross before business expenses. I run a home day care and actually I net very little after paying my employees. To add insult to injury they are now asking for a medical evaluation and a psychological evaluation on a 15-month old child who has Down Syndrome. How ridiculous. It's enough to discourage anyone.

Moreover, the parent of a 12-year-old boy with a chronic illness wrote, "Government (state & fed) needs to look at the policies to help parents of children w/ disabilities. We are in a parent/stepparent/disabled child and we have had numerous [losing] situations with both state & fed. It has been completely unfair to the child."

Table 15
Responses:
State and community agencies provide financial help for disabled persons who cannot work but who need support while appealing Social Security or SSI benefit denials or while waiting for benefits to start

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.7	4.2	1.7	2.9	3.0	3.1	3.2	1.7	1.1	3.5	2.7
% 2	1.1	0.5	1.3	2.2	0.7	0.5	0.5	1.7	0.5	0.0	1.1
% 3	3.9	8.8	7.3	4.8	3.7	7.2	4.3	5.1	2.7	3.5	6.0
% 4	11.0	14.4	11.0	11.0	6.0	13.9	8.6	11.3	9.3	9.1	12.5
% 5 (Very important)	82.3	72.2	78.7	79.1	86.6	75.3	83.4	80.2	86.3	83.9	77.7
Mean	4.7	4.5	4.6	4.6	4.7	4.6	4.7	4.7	4.8	4.7	4.6
n	181	216	301	273	134	194	187	177	183	143	1004
% 1 (Not satisfied)	45.4	36.7	47.7	47.1	58.9	43.5	43.9	40.6	55.4	53.5	43.3
% 2	22.1	18.6	18.1	16.9	17.7	22.6	20.7	21.9	17.7	16.3	18.9
% 3	18.4	28.2	24.5	26.3	12.9	22.6	22.0	25.0	13.7	23.3	25.9
% 4	6.7	6.9	5.1	5.9	4.0	7.3	6.7	6.9	6.3	3.1	5.9
% 5 (Very satisfied)	7.4	9.6	4.7	3.9	6.5	4.0	6.7	5.6	6.9	3.9	6.0
Mean	2.1	2.3	2.0	2.0	1.8	2.1	2.1	2.2	1.9	1.9	2.1
n	163	188	277	255	124	177	164	160	175	129	900

Table 15 documents the strong belief that "state and community agencies [should] provide financial help for disabled persons who cannot work but who need support while appealing Social Security or SSI benefit denials or while waiting for benefits to start." Nearly all respondents ranked this need as highly important. In their written comments, many complained about the long delays in obtaining necessary benefits. For example, a 24-year-old woman with a psychological impairment and a chronic illness wrote,

> I am NOT happy with this system at all! I have a 4 yr. old handicapped daughter who does not receive benefits and a 2 yr. old daughter who is not handicapped. I'm a single mother with bipolar and struggling with many problems and trying to maintain some kind of home for my children. My doctors refused to let me work. I begged and pleaded with the state for financial assistance, their response was "as long as my case is pending I CAN NOT receive assistance, once I am approved then I can apply for my 2 yr old.' I was [in] low-income housing. .... Now I am 'homeless', still 'appealing' with social security, and no one will dare help me. I keep getting referred to the nearest shelter or given the name of a lawyer I can hire. Hello! Does anyone out there understand "NO MONEY", "I NEED HELP."!

Similarly, a 47-year-old woman with several disabilities (mobility, neurological, chronic illness and other) described how delays in obtaining needed benefits threatened to plunge her into financial chaos. She wrote,

> My husband and I are disabled. .... My husband and I have been discriminated against by numerous institutions and agencies. I have been turned away and denied treatment by the Family Practice Center in Liberal, Kansas...due to my inability to pay my bill and I am an indigent patient. This facility was founded for indigent people and now they are going back on their oath and mission. Also, the electricity department has threatened to turn off our services due to our inability to pay the bill. Third, I have to have water therapy treatments for my disability and the water company turned off our water several times. This conflicted with my treatments. Fourth, back medical bills have now been sent to a collection agency and I am being [harassed] by debt. collectors.. I barely make it through the month on my funding. I need [Medicaid] help NOW! I also need [Medicare] Insurance benefits — NOW! I can't afford to wait 2 years to get these benefits. Financially, I am sinking. The medical care I need I can't receive, because I don't have Medicare benefits. Help!!!

A 32-year-old woman with a visual impairment wrote, "Why is it taking so long just to [hear] about my status on my case. It has been over 60 days" and a 47-year-old man (neurological disability and chronic illness) described the process of applying for Social Security Insurance as "a long and taxing process for the disabled." The parent of a 12-year-old boy with a variety of disabilities (visual, neurological, psychological, speech, learning and mental retardation) also expressed frustration with the state's long waiting periods.[16] She wrote,

> I am the parent, daughter, aunt and granddaughter of disabled peoples. I am also a nurse. To say our state is inadequate for the physically and mentally disabled is a great understatement. My son receives SSI & Medicaid. He also was on the list for 6 years for SSI/DDSD [Supplemental Security Income/Developmental Disabilities Service Division] services; this was too long.

Similarly, a 40-year-old respondent with a psychological disability asked,

> Why do disabled people have to [always] take second seat to everything. What little money that I get [goes] on bills so that means I have to live in a shack or be [homeless because] it takes housing 2-6 years to get me on the list to get a house.

A number of respondents seemed worn out by long delays and repeated rejections in their efforts to obtain governmental support. For example, the parent of a 41-year-old man with a variety of disabilities (neurological, psychological, speech and mental retardation) wrote,

> I have been trying to get my son help for the last 3 and 1/2 years from Social Security. He is fortunate that he is part Indian and gets some medical help through them. The doctors he has seen with the Indian Agency say there should be no problem getting help, but that has not been the case. When he is sent to the doctors Social Security employ, they say he is able to do a job he had 4 years ago at Tinker. (They laid off the handicapped workers, my husband filed suit for them and other handicapped. Subsequently, they re-hired all but my son. My husband passed away in 1997 and I was unable to continue the suit.) He has been turned down 3 times for Social Security and as of Aug 15, 2001, he has been denied an appeal. .... His total income last year was around $3200. .... It worries me, since I must provide the income to get him going. I am a 65-year-old widow with very little income and in poor health myself. No one in my family or my husband's large family have ever drawn help and have all worked hard all our lives, yet when in need, we cannot receive.

---

16. In 1997, Sharon Davis prepared "A Status Report to the Nation on People with Mental Retardation waiting for Community Services." Many states, including Oklahoma, "now use the Medicaid Home and Community-Based Waiver, which allows Medicaid to pay for community options for people who are in an institution or at risk of going to one. The waiver can be used to move people out of institutions. It can also be used to provide community residential services to people on the waiting list, particularly those with urgent needs. Waiver services typically cost considerably less than institutional services, allowing a state to serve more individuals" (Davis 1997: 10, 13). Davis (1997) found that Oklahoma had the twenty-third longest waiting list among all states, with 61.4 community services needed per 100,000 state population. (Louisiana headed the list with 320.3 services needed per 100,000 state population.) As Davis states, "the existence of a waiting list can be cause of litigation" (Davis 1997: 9).

A 64 -year-old woman (mobility impairment and chronic illness) reported that

> Getting my Medicaid has been an 'ongoing nightmare' since I became disabled by state disability on Jun 27.01. It is just today — Oct 22.01 that I finally got it straightened out. The DHS people would not even return my calls — They had input information incorrectly and I have had to do without medication after suffering a heart attack. I finally had to threaten to call the governor's office to get a return call and straighten this out. It is criminal when 'Oklahoma doesn't take care of its own.'

Most ODS respondents feel that the state urgently needs to provide some sort of support for individuals waiting to receive benefits. The mother of a 4-year-old boy with speech impairment and a learning disability described her situation:

> My son Joshua was recently diagnosed with PDD-NOS [Pervasive Developmental Disorder — Not Otherwise Specified] (with signs of autism). If there would have been supplementary therapy available while a diagnosis could not be made, I believe it would have been quite helpful...We hope that perhaps one day people won't have to go through as much 'headache' to obtain this assistance.

Respondents agree that the employees of many government agencies tend to be rude, unresponsive, and apathetic. A 48-year-old woman with a hearing impairment wrote,

> Oklahoma is certainly way behind in providing services for people with disabilities. Also Oklahomans certainly need a huge sensitivity training counseling their attitude towards disabled people. They are rude beyond belief. Many of these [government] programs move so slow it really causes you to want to quit. If a person needs help now he cannot wait 4 months.

Similarly, the parent of a 21-year-old man with multiple disabilities (visual, mobility, neurological, psychological, speech, learning and chronic illness) wrote,

> There is a very limited amount of help. Medicaid [employees] have <u>no</u> respect for their clients and they don't care about their clients. There is <u>no</u> help with food, pills or PT [Physical Therapy], OT [Occupational Therapy], or speech. If you turn 21 you might as well be dead because they don't care. If you are trying to keep your loved one at home and out of nursing home there is <u>no</u> help. I would love to know where our state money goes and why they don't check out the frauds who are getting help. .... If you need help getting food for your loved one [forget it] once they turn 21, they cut you off. They do not believe anything you do or say about your loved one nor do they care. I have cut my son back on everything thinking I was helping our state, now I have realized they don't <u>care</u>. I have gone to get help, called to get help and I have been lied to and [been given] the wrong information just so they can get rid of me. Plain and simple <u>This</u> <u>State</u> <u>Don't</u> <u>Care</u>....

Quite a few respondents are concerned that able-bodied individuals are receiving funds which could be better spent on those with disabilities. The parent of a 30-year-old woman living in a nursing home wrote, "Get the bums off welfare!! Give it to those who can't work." Similarly, the parent of a 10-year-old boy with a hearing impairment wrote,

> I believe it can be difficult for the government to provide all the needs of the disabled due to the abuse of those who do not really need financial help or do not really have a disability that prevents them from working.

A close relative of a 30-year-old man with a psychological disability described how many people take unfair advantage of government services:

> I feel there is way [too] much abuse of the system by those who are fortunate enough to receive SSI. I personally know of a couple people who truly have abused the system and while knowing they are wrong continue to do so. .... At the same time one person I know that truly needs the help and can't even afford to see a doctor is doing without. He can't get approved for SSI because he has had to work to support himself and despite several [attempts] still [cannot] get on it even though he's currently not working.

Similarly, a 41-year-old woman with a mobility impairment described how she has been turned down for benefits which she felt she deserved:

> I went to Department of Human Services to apply for financial help and food stamps, because I have no income since Jan. 7, 2000 and my husband's pay isn't enough for a family of 4. I also applied for SSI and SSD but they turned me down too. The DHS said because I have a car that is [worth about $9,000] so I don't qualify. In other words I have to have a junk car that needs [constant] repair and bring me in some more debt to qualify. My savings are gone and now I have to spend my [children's] saving bonds. Nobody is helping in the time of need unless everything is lost — house, car, etc. and the person has to be on [welfare]. I guess the government likes to have people going on [welfare] before they help instead of helping out before it comes so far. My workplace is letting me go because I'm unable to perform my job. I know I'm not the only person who gets disabled but I feel I'm alone; no help from any of the agencies. There are people here who could work with no problems and get SSI & SSD; I met so many and then there are people like me and others — who can't even walk or sit on the floor with my infant to play and get nothing. I'm really worried that I'm going to [lose] my house before Christmas!!!

Accommodations in the Schools

Table 16
Responses:
Effective academic programs are available for disabled students

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	2.2	5.0	1.0	2.2	0.8	3.1	1.1	0.6	2.8	2.8	2.7
% 2	0.0	0.9	0.7	1.5	1.5	0.5	0.5	0.0	0.6	0.0	0.7
% 3	3.3	4.5	3.4	5.5	3.8	3.1	1.1	3.4	5.6	2.8	4.6
% 4	10.0	12.6	12.5	12.2	13.1	12.4	10.2	10.3	17.9	9.7	12.4
% 5 (Very important)	84.4	77.0	82.4	78.6	80.8	80.9	87.1	85.7	73.2	84.7	79.6
Mean	4.7	4.6	4.7	4.6	4.7	4.7	4.8	4.8	4.6	4.7	4.7
n	180	222	295	271	130	194	186	175	179	144	999
% 1 (Not satisfied)	33.3	28.4	29.7	31.2	38.8	38.2	42.1	40.7	29.7	35.7	29.4
% 2	16.4	14.9	16.8	20.2	17.4	19.7	18.7	19.8	16.4	11.6	17.9
% 3	29.7	30.8	37.4	33.2	24.8	26.4	19.9	23.4	37.0	36.4	32.7
% 4	12.1	13.9	9.5	11.1	11.6	10.1	9.4	9.0	10.9	9.3	12.5
% 5 (Very satisfied)	8.5	11.9	6.6	4.3	7.4	5.6	9.9	7.2	6.1	7.0	7.6
Mean	2.5	2.7	2.5	2.4	2.3	2.3	2.3	2.2	2.5	2.4	2.5
n	165	201	273	253	121	178	171	167	165	129	906

Inadequacies in the state's educational system were cited by a substantial proportion of respondents. (See Table 16). Moreover, approximately 1 in 5 respondents (who provided written feedback) made some reference to problems in the state's educational system in their written comments. Many parents have fought long (and frequently losing) battles with the schools, and many are frustrated by an often blatant disregard for laws that require accommodations for students with disabilities. The mother of a 10-year-old boy with multiple disabilities (visual, mobility, speech and mental retardation) wrote, "I am surprised at how hard parents have to fight to get correct services for a child in school. It should be that the teachers want what's best for children." Similarly, the parent of an 11-year-old boy with visual, mobility, neurological, speech, and learning impairments stated, "You have to fight the school systems for the services that are needed so you can receive an education just like everyone else." One respondent wrote "Are you kidding!" next to this survey question, and another wrote "Bartlesville schools are horrible in this <u>area</u>."

Many respondents feel that the schools either disregard the rights of individuals with disabilities or provide only the minimum level of service necessary to comply with legislation. For example, the parent of a 16-year-old Ottawa County girl with learning disabilities wrote,

> In our area we have a serious problem with our school systems feeling that a disabled child with a learning disability is taking too much time & effort to teach & it's not fair to the <u>NORMAL</u> students. What happened to every [child's] right to a free & appropriate

> education? Let's stop this discrimination. We need some kind of penalties or criminal punishment for school faculty & administrators that routinely discriminate against learning disabled children!!!!!!

Likewise, the parent of a 10-year-old Tulsa County boy with a speech impairment and mental retardation stated,

> School districts, [particularly] certain districts, have no intention of following the IDEA[17] nor do they care about what is in the best interest of the person with a disability. If they perceive they are meeting the person/student's needs, in most cases they are naive and usually underestimate potential. There are select districts or schools that do provide a quality education, but they are few and far between.

Several respondents indicated that the schools did not comply with federal legislation requiring Individualized Educational Programs (IEPs).[18] The parent of a 17-year-old Canadian County boy with a learning disability explained:

> I also believe that people with learning differences, which are not obviously apparent, are not getting the support needed at school. IEPs [Individualized Educational Program] are not being followed and often teachers are not aware of supports that are written into IEPs.

Another respondent, a 20-year-old Ottawa County man with a hearing impairment, feels that "Teachers verbalize compliance with [IEPs] & sign their names, but most leave it at the table & it becomes necessary for students to make their own [accommodations]." The sense among many ODS respondents is that violations of state and federal law are not taken seriously by the schools. The parent of a 10-year-

---

[17] What is now referred to as the Individuals with Disabilities Education Act (IDEA) was originally enacted by Congress on November 19, 1975, as Public Law (PL) 94-142. At that time it was called the Education for All Handicapped Children Act of 1975. IDEA, the Individuals with Disabilities Act, mandates the provision of educational services to meet the educational needs of eligible children.

[18] The Education for All Handicapped Act of 1975, now referred to as IDEA, requires that an Individualized Education Program (IEP) be developed by a team of educators for each eligible child or youth with a disability. An Individualized Educational Program (IEP) describes the special education and related services specifically designed to meet each child's unique educational needs. On June 4, 1997, President Clinton signed into law PL 105-17, the Individuals with Disabilities Education Act Amendments of 1997 (IDEA '97). The 1997 IDEA required some changes in the IEP's. For example, the IEP team now includes the regular education teacher; student involvement in the general curriculum is greatly emphasized; and parents must now be included in the group that makes decisions regarding their child's educational placement. For a summary of the requirements for the IEPs as amended by IDEA '97, see WETA (2002).

old Noble County boy with speech and learning disabilities wrote,

> The State Board of Education is...very negligent on policing principles and teachers regarding classroom policies and practices. The "School Board" is supposed to be responsible for this but that's just a bunch of untrained, unsupervised people, who when faced with a problem are going to shove it under the table so their government funding won't get cut and their records won't be tarnished. Children are held accountable to teachers and [principals] for their actions but who holds teachers [principals] accountable for their actions? When said people are not going to air [their] "dirty laundry" for inspection because they know that parents of children with disabilities can't necessarily afford to get legal [aid] because children with disabilities are high financial [maintenance].

Several respondents were clearly worn out from battling the school system. The parent of an 11-year-old Tulsa County boy with a hearing impairment wrote,

> I think the educational opportunities in Oklahoma are pitiful. I find most of the time my child is expected to fit the program, not that a program should be designed to meet his needs. His reading level is two full grade levels behind and yet the school doesn't feel he needs any extra assistance to catch up beyond what they offer in the classroom. They made it clear I was free to hire a tutor if I feel he needs extra help. I know I could fight them legally, and I might even win. But if I use my energy for that prolonged battle we waste valuable time — because as a parent of another child too — I can't use every ounce of energy on my disabled child. The schools know most parents don't have the time, energy, or financial resources to fight them — so they offer the minimum and we take it. Sometimes I hate myself for that.

Similarly, a 54-year-old man with mobility and neurological impairments expressed his concern with the schools' handling of disability rights issues:

> They refuse to help unless threatened with lawsuits. They intimidate parents of disabled students. I have personal examples of this and would be happy to be a part of a class action against the local [Washington County] system. They are interested only in saving money & could not care less for a quality education for students.

Another respondent, the parent of a 3-year-old child with a mental disability, wrote,

> Many school districts in Oklahoma say that have full "inclusion" and they are nowhere close to states such as Calif. Ex: Union school district in Tulsa County did not even want to discuss long range parent planning committee. Insisted they had full inclusion already. Smaller communities in Oklahoma may not have information as readily available.

A number of respondents complained that the schools were uninformed about legal requirements and were not forthcoming with information about how to obtain necessary services. For example, the parent of a 10-year-old boy with multiple disabilities (speech, learning, mental retardation) wrote,

> It seems that services are only available if you know what to ask for: Schools don't volunteer service availability. In talking w/ parents of other disabled children, the appearance of great disparities in levels and provision of services exist in different school districts — our district, Owasso's, attitude seems to be, 'how little can we do and still be within the law?' I think it should be "how much could we do to help these students and parents?"

The parents of children with developmental disabilities were often especially upset by the schools' failure to give their children a good education. The parent of a 14-year-old Okfuskee County boy with several disabilities (speech, learning, mental retardation and autism) wrote, "The schools just put up with them & pass them on to get them out of the way; instead of helping them become productive parts of the community." A 22-year-old woman with impaired hearing and mental retardation likewise noted that teachers and administrators "don't want" individuals with disabilities in the schools. Another respondent claimed that teachers and administrators "try & overlook" individuals with disabilities.

Oklahoma schools also drew criticism for their failure to recognize the needs of individuals with "hidden" disabilities. For example, the mother of a twelve -year-old girl with a learning disability wrote, "I feel schools offer better services of physical handicaps than mental or psychological or emotional[;] they [want] to slough it off as a behavioral problem instead of the real problem it is. .... You have to fight for your [kids'] rights." One 19-year-old man described a similar situation:

> I have found that neurological and speech disabilities are not considered by the general population, school administrators, school counselors, teachers...etc. as true disabilities. AND [the schools] are not willing to easily provide [accommodations] without my parents having to go to school and FIGHT every year for [accommodations].

Many respondents feel that Oklahoma schools have unacceptably and unrealistically low standards for disabled students — particularly those with developmental disabilities. The parent of an 8-year-old Osage County boy with several disabilities (hearing, psychological, speech, learning and mental retardation) stated that

> Our school just wants to pass him up without even trying to educate him. So since they do not have him an aide in school yet I am going up after work to help him do his work. I know my child is able to do the work with help [but] they keep stalling because they don't want to pay for it.

A similar sentiment was expressed by the parent of a 14-year-old Wagoner County boy with psychological and learning disabilities:

> Our biggest downfalls have been with the schools and legal authorities. I have had to fight with the school for every tiny thing and still my son is not being taught to read. Due to a law saying that schools do not have to hire special teachers that regular ed. teachers can teach the class for one year my son gets "babysitters" that are not trained for the situation. Instead he would color or be told to go to sleep. And the class gets a new teacher each year. I am told that because of money services cannot be rendered such as reading programs or aides. Instead the school [harasses] parents until the child is 16 and then drops out of school. They only will give you what you know about they never tell of services available or offer suggestions. And even sometimes you must threaten them. Then when you do that you are labeled a trouble maker and your child is suspended for stupid things like rolling pennies on the playground.

Some parents have opted for home schooling due to their frustration with their local school systems. The mother of a 17-year-old Grady County boy with multiple disabilities (mobility, speech, learning and mental retardation) wrote,

> I live in a small town. My child is home schooled due to health reasons and "Thank God" for that. Because if one more teacher asks me "Well, what am I to do with him" I'm truly sorry for what I might say or do! Wake-Up Parents we've got to get "Louder" because for some reason the <u>men</u> & <u>women</u> on the hill can't hear us.

Support Services in the Schools

Table 17
Responses:
Adaptive educational materials and needed support services
(i.e., speech therapists, translators, etc.) are readily available to disabled students

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.7	3.6	1.0	2.2	1.5	2.5	0.5	0.6	2.8	2.8	2.4
% 2	0.0	0.0	0.3	0.7	1.5	0.0	0.5	0.0	0.6	0.0	0.4
% 3	3.9	7.7	3.0	5.9	4.6	2.5	1.6	1.7	8.3	4.8	5.8
% 4	11.2	12.6	11.8	11.9	10.0	10.1	9.5	10.9	13.3	13.1	12.7
% 5 (Very important)	83.2	76.1	83.8	79.2	82.3	84.8	87.9	86.9	75.1	79.3	78.7
Mean	4.7	4.6	4.8	4.7	4.7	4.7	4.8	4.8	4.6	4.7	4.6
n	179	222	296	269	130	198	190	175	181	145	1001
% 1 (Not satisfied)	30.2	29.5	25.1	28.3	33.1	37.9	36.0	33.3	25.9	28.6	25.0
% 2	23.5	20.0	21.7	22.7	24.0	24.7	21.5	22.8	17.5	16.7	21.7
% 3	27.2	23.0	34.5	31.9	23.1	21.4	24.4	26.5	38.6	34.9	32.1
% 4	13.0	16.0	10.1	10.0	10.7	7.7	7.0	8.6	12.0	11.9	12.2
% 5 (Very satisfied)	6.2	11.5	8.6	7.2	9.1	8.2	11.0	8.6	6.0	7.9	9.0
Mean	2.4	2.6	2.6	2.5	2.4	2.2	2.4	2.4	2.5	2.5	2.6
n	162	200	267	251	121	182	172	162	166	126	893

Many ODS respondents worry that it is nearly impossible to get the schools to provide the adaptive equipment and services that their children need. While virtually all respondents rate this need as very important, fewer than 10% are "very satisfied" that the need is being met. (See Table 17.) The mother of a 10-year-old boy with multiple disabilities (visual, mobility, speech and mental retardation) wrote next to this question, "It takes an act of congress." Similarly, the mother of a 14-year-old girl with a speech impairment stated,

> My daughter doesn't have severe disabilities. She has a slight speech problem, eye/hand coordination, fine motor skills problem and a behavioral problem (high social anxiety). The McAlester public school where she [attends] told me she needs occupational therapy yet they never got around to visiting her & also she needs to see a psychiatrist/psychologist & they were going to contact me about that last summer & [I've] not heard from them yet — I was able to put her on Sooner care for 6 months now that my son has turned 18 we no longer can

> get it — during that time the school was [supposed] to set up an appointment with a psychotherapist but never did — so I'm not happy with special services at the school whatsoever.

Several respondents complained about the schools' reluctance to provide occupational therapy, physical therapy or speech services. For example, the parent of a 14-year-old with a variety of disabilities (speech, learning, mental retardation, and other) living in Okfuskee County wrote,

> More help is needed for school age children that are disabled so they will be able to make it & support themselves. The schools say they can't afford, PT [physical therapy], OT [occupational therapy], speech, [etc.], therapy as needed for these kids but can afford sports activities for non-handicapped kids. Handicapped kids are not encouraged in fact discouraged from extra activities in school like sports, band, plays, [etc.]. Parents of handicapped kids have to work, talk & fight harder to just get the basics for these kids.

Similarly, the parent of a 13-year-old boy with neurological, psychological, and learning disabilities wrote,

> The Broken Arrow School system fought us hard so they would not have to provide my child needed services. They have wasted 7 of my [child's] years. We have finally gotten some services but we still are fighting for O.T. [Occupational Therapy] and speech services a...[psychologist] says he needs. And we have had to fight alone because [there's] no easy help available.

The parent of a 3-year-old girl with multiple disabilities (hearing, mobility and speech) expressed similar concerns:

> I think deaf-educators should have the same access to ongoing education/workshops that emphasize S.E.E. [Signing Exact English] as they do the A.S.L. [American Sign Language] dominated educational opportunities.[19] It would be nice if [the] M.W.C. [Midwest City] public [school] system was more timely in picking up O.T. speech needs of children who age out of Sooner Start. It took us over 1 year to get any response at all from them, & has now been 1½ yrs. We have yet to hear what they have to offer. Kids who go to private schools should have the same access to S.E.E. or A.S.L. interpreters as public school educated kids.

The parents of a 7-year-old Oklahoma County boy with a speech impairment and mental retardation became so frustrated with the school's lack of accommodation that they opted to pay for the necessary

---

[19] American Sign Language (ASL) is "used by many deaf in the United States, thus its use promotes assimilation into the Deaf Community. ASL is a visual language, and speechreading or listening skills are not needed to learn ASL fluently. ... SEE [Signing Exact English] is based upon signs drawn from ASL and expanded with words, prefixes, tenses, and endings to give a clear and complete visual presentation of English. The ASL sign for the concept of "pretty, lovely, beauty, beautiful" and other such synonyms is retained for beauty, initialized with P for pretty, L for lovely, and the suffix -ful is added for beautiful. The child thus has an opportunity to develop an expanded vocabulary. The learning of this English based sign system may be more comfortable for English-speaking parents" (Listen-Up! 2002).

services out of pocket:

> There is a problem with service from age 3 until kindergarten in the smaller school districts. Sooner Start stops service when the child is 3 and the school is supposed to provide the service from that point on. The current school district does provide such service, but the district we lived in when she was that age could not provide anything so we paid for speech and physical therapy ourselves.

Many parents feel as though the schools are unwilling to make the investments necessary to ensure accessibility for children with disabilities. For example, one parent wrote, "My school district was 0% accessible equipment on playgrounds, which doesn't meet ADA requirements." Likewise, the parent of a 20-year-old Grady County man with a neurological disability and mental retardation complained that the schools actively discriminate against children with disabilities:

> In school, especially grade school, I [have] seen the LD [Learning Disabled] labs misused. Problem children seem to be sent [there]... The special ed class was placed outside the main building at times while 'normal' children had access to classes easy to get to, easy to get to the bathroom, etc.

Several parents argued that the schools had not prepared their children for the real world — that teachers and school administrators had failed to provide the academic and vocational skills necessary to help their children become functionally independent adults. For instance, the parent of a 17-year-old girl with a hearing impairment complained that the local school would not "educate her [my daughter]" and that there was "no [opportunity] to develop [into an] adult who could care for herself." The parent of a 24-year-old Washington County man with a neurological disability wrote,

> Our son has a neurological problem since 7 that has greatly [affected] his life. School in Tulsa was a joke. Transferred to Jenks from Union was better but he was never trained for life skills [such] as how to get/keep a job.

A parent expressed similar concerns with regard to his 19-year-old son, who has a learning disability and mental retardation:

> I was very displeased with services & referrals for help when my child was younger, and I was shocked that the teachers at your schools could not help me on certain issues or refer me to the right people. And then I was displeased when he graduated from high school, I thought he was to be helped in gaining employment; I was told he had been signed up for a job, which was a lie in the end, and now I'm still trying to help which is not good, is it who you know?

Dissatisfied with local public schools, a few respondents have opted for alternative educational arrangements. Some have chosen home schooling while others have moved or sought out alternative schools. One respondent wrote, "My experiences with public schools was not a positive experience. My son attended Okla. School for the Deaf. If it had not been for the academics my son would have been [severely] delayed socially as well as academically." Another parent, whose daughter had a variety of disabilities (speech, learning and mental retardation), reported that

> Public School is not what it needs to be for children with disabilities. My daughter has to be sent 3 hrs away to get the special needs she receives because the local school [can't] & [won't] provide for her... My daughter is attending OSD [Oklahoma School for the Deaf] on a trial because this being a school for the deaf they are trying to find a way to accept her even though she isn't deaf only mute & with developmental delays. OSD is really [an] excellent place & is trying real hard to help her. I'm real pleased with their efforts.

The parent of a 7-year-old Oklahoma County girl with a speech impairment and mental retardation stated that moving from one public school to another can be helpful: "I am very pleased with...our current public school, but we did move to a new school district since the previous school was too small to offer all she needed." Another respondent, a 21-year-old man with a hearing impairment, described how he experienced such terrible discrimination in the public schools that he transferred to the Oklahoma School for the Deaf (OSD):

> I'd like to say that I am very familiar with public discrimination. It happens everywhere [and] I've had [many] experiences. In public schools, I was always made fun of and when something happened fingers were pointed my way and school administration were always in favor of discriminators stating that it was always an assumption. I endured [rejection] and humiliation so I transferred to Oklahoma School for the Deaf.

Meanwhile, the parent of a 15-year-old girl with several disabilities (mobility, neurological, speech, learning and mental retardation) suggested more specialized schools for individuals with disabilities:

> [I] would like to see at least one school in each state designed specifically to meet the various needs of those affected w/ severe disabilities. It is impossible to expect ea. school district to provide the necessary interventions. The cost to a rural school would be unreal. Renovation, equipment, therapist, one on one, etc.

The experiences of a 43-year-old woman with speech and hearing impairments demonstrate another side of the problem — how parents with disabilities can be cut off from their children's school activities. Citing a lack of accommodation, she wrote,

> Schools/Teachers/PTA needs to be [accessible] for disabled parents of nondisabled children who attend their schools! I've often, if not always, been left out of my children's school activities ex: plays, performances, teacher meetings because I am hearing impaired.

Lastly, concerns about accommodations and accessibility were not limited to primary and secondary schools; several respondents described the obstacles they encountered at institutions of higher learning. For instance, a 48-year-old woman with a psychological disability and chronic illness stated that "[accommodation] for those with hidden & mental disabilities is not an easy (often it fails) process at the [university] such as O.U. The process is not always fair and teachers do not always understand why [accommodation] is so essential."

School Teachers, Administrators and Counselors

Table 18
Responses:
School administrators and teachers are sensitive to the needs of disabled students

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	2.2	4.5	1.7	1.9	1.5	2.6	2.2	0.6	2.8	1.4	2.5
% 2	0.0	0.0	0.0	0.4	0.0	0.0	0.0	0.6	0.6	0.0	0.3
% 3	2.2	4.0	2.7	4.5	3.8	3.6	2.2	1.1	7.2	4.8	3.9
% 4	7.3	13.5	9.9	10.5	8.4	8.7	6.5	8.0	8.3	6.2	9.8
% 5 (Very important)	88.3	78.0	85.7	82.8	86.3	85.1	89.2	89.7	81.2	87.6	83.5
Mean	4.8	4.6	4.8	4.7	4.8	4.7	4.8	4.9	4.6	4.8	4.7
n	179	223	294	267	131	195	186	174	181	145	998
% 1 (Not satisfied)	31.1	26.0	24.8	29.1	34.7	30.9	37.8	35.3	20.5	32.3	26.3
% 2	21.0	21.6	25.2	23.1	19.8	24.9	19.4	22.2	27.1	14.6	21.6
% 3	27.5	24.5	30.0	29.9	22.3	24.3	20.0	25.1	33.1	30.0	29.0
% 4	12.0	15.7	10.7	10.8	9.1	8.3	11.7	9.0	12.7	13.8	13.8
% 5 (Very satisfied)	8.4	12.3	9.3	7.2	14.0	11.6	11.1	8.4	6.6	9.2	9.3
Mean	2.5	2.7	2.5	2.4	2.5	2.4	2.4	2.3	2.6	2.5	2.6
n	167	204	270	251	121	181	180	167	166	130	904

For many students with disabilities, school-related problems are not limited to support services and accommodation issues. Specifically, many parents feel that teachers and administrators are insensitive and unprepared to address the needs of children with disabilities. Table 18 suggests the extent of the problem. Moreover, 69 respondents (or 15.2% of those who provided written comments) expressed some concern relating to school teachers, administrators and/or counselors.

One of the most revealing — and disturbing — themes that emerged in the surveys was the frequency with which parents complained that their children, especially those with developmental disabilities, had been neglected or physically abused in the schools. The parent of a 9-year-old Cleveland County girl with mental retardation and a speech impediment expressed fears for the safety of his/her daughter:

> In the school district where my child attends we face total ignorance in regards to [a] child with mental disabilities. .... The social problems she has faced in past 24 months while being at the present school range from total discrimination and acts of violence to molestation. Each time, the problems were addressed with the school principal, her response remained each time, 'That kind of [behavior] does not happen in my school.' I have had to become a staunch patrol of safety practices for my child even to the point of meeting with school administration to ensure that my child's safety was of paramount concern to everyone whom she came in contact with. I would gladly assist in any changes that could be made statewide in regards to ensuring the safety of our children with special needs.

Similarly, a Tulsa County parent described the abuse encountered by his/her 20-year-old son:

> My son has a mental illness. He also has learning disabilities and ADHD [Attention Deficit Hyperactivity Disorder]. Once he reached Jr. High and High School, we found the teachers resisted following the IEP and actually discriminated. They were resentful that they'd be told what to do in their classroom. There were teachers who hit and pinched him or allowed it to happen in the class setting — even documented it. They expected the child to behave better than they. Later, I learned some teachers were "reprimanded", but never openly. How sad. They did a lot of damage emotionally. The other students observed the obvious mistreatment and often told me about it. We tried to intervene but it was a [losing] battle. The system of justification & excuses was so entrenched. He turned out well, though not academically educated, in spite of them.

The mother of a child with Down Syndrome in Grady County wrote,

> I have a child with Down syndrome who is constantly within the special education system and the regular school system being discriminated against daily. They isolate the students and do not allow much social interaction with the other students. However, they do expect retarded children to understand the rules and are very punitive in their punishments towards [them] when they are not capable of understanding the rules and what is expected of them. I refer to the Chickasha School System. Pro Oklahoma [Parents Reaching Out in Oklahoma][20] has been of no help in this community. There are no advocates for the disabled students at all. The ones in charge have very little training or sensitivity to the needs of [handicapped] students.

In some cases, parents have had to seek legal assistance in order to stop abuse. For example, the mother of a 12-year-old Cherokee County boy with a multiple disabilities (visual, neurological, psychological, speech, learning and mental retardation) wrote,

> I have had to resort to having my son's school record sent to [the] Ok. Disability Law [Center] to stop the school from putting him in a tie-down chair or paddling him for defending himself in the classroom against the para-professional. And this is only part of what we go through all the time.

Several respondents voiced a concern that school teachers and administrators were uninformed about how to accommodate individuals with disabilities. For example, one respondent stated, "I had to provide [adaptive] materials — because the teachers don't generally know how to accommodate." The parent of an 8-year-old Marshall County girl with visual and mobility impairments complained about the

---

20. PRO-Oklahoma (Parents Reaching Out in Oklahoma) is a statewide project that provides training and information for parents of children with disabilities. The PRO-Oklahoma Parent Training and Information Center provides workshops on basic rights, IEPs (Individualized Educational Programs), communication skills, early childhood transitions, and school-to-work/home-to-community transitions (Internet Special Education Resources 1999). As of Fall 2000, PRO-Oklahoma changed its name to "Parents' Center."

quality of special education teachers:

> <u>School System Issues</u>: .... [Pre-judgment] is standard. Expectations are low or nil. — they tend to follow letter of law explicitly — except paperwork looks wonderful except quality of services are actually much less in [actuality] — Need to improve the quality of specialty teachers used as consultants. Improve standards to become certified. Centralized [committee] that the people report to and check the abilities of those [who] provides services, ex: VI [visual impairment] consultants that pass a test after 2 months of instruction — how can someone humanly possibly learn how to aid children's education [dramatically] after so little time. Our VI teacher doesn't know braille but is supposed to teach my child braille??? .... Ready to label children MR [Mentally Retarded] ... They would rather belittle the child's abilities than [their] own lack of needed instruction. Perhaps the introduction of parent and student advocates statewide in each school district appointed by the state to trouble-shoot and head off potential problems.

Meanwhile, the parent of a 21-year-old with a hearing impairment wrote, "Some of her [my daughter's] public school teachers were very good teachers & [accommodating]... Others, just didn't 'get it.'" The parent of a 4-year-old Marshall County child with several disabilities (hearing, learning and other) suggested rewards for special education teachers who do a superior job:

> <u>[Special] teacher & aides should get a raise in pay that are doing a good job</u>. There are some out there that are just there for the pay. <u>And some that put [their] heart [into] it & love working with the kids & older people!!!</u>

In some cases, school personnel may have misdiagnosed children's disabilities. The parent of an 8-year-old boy with visual and speech impairments wrote,

> [The] schools are not [equipped] to meet the needs of handicapped students. Also they fail miserably in adequately evaluating children and their real needs. Our son was misdiagnosed and spent 3 years in a class for emotionally [disturbed] children. His true needs are just now beginning to be met and we had to take him to an outside clinic in order to get the school system to start meeting his true needs.

Similarly, the parent of an 8-year-old boy with a variety of disabilities (psychological, learning, and other) wrote,

> I am concerned for my [son's] future as [the] school has misdiagnosed him grossly for ADHD when it is emotional & psychological [problems]. ... This has caused him extra problems by doing so, by violating his rights being rude, sending him to police station in 1st grade, it is a constant battle to fight for his education. He has a good mind [and a] high [intellect], but [the] school lets his behavioral disabilities stand in way of giving him a good education. I am not in access to good alternative education for him. The public schools need to be forced to deal with all students on [an] equal basis as to [their] needs [and] not restrict them from outings, etc.

Day Care and Aftercare

Table 19
Responses:
Day care programs are available for disabled children

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	6.1	7.2	7.0	6.0	3.0	6.5	5.8	5.6	6.5	7.0	6.6
% 2	2.2	1.4	2.5	3.5	0.8	2.0	1.6	3.9	1.6	1.4	2.5
% 3	7.8	7.2	8.3	9.2	12.0	6.0	6.3	8.9	7.6	4.2	7.9
% 4	15.6	19.5	18.7	20.9	15.8	18.0	14.1	13.3	19.6	11.9	16.6
% 5 (Very important)	68.2	64.7	63.5	60.3	68.4	67.5	72.3	68.3	64.7	75.5	66.4
Mean	4.4	4.3	4.3	4.3	4.5	4.4	4.5	4.4	4.3	4.5	4.3
n	179	221	315	282	133	200	191	180	184	143	1013
% 1 (Not satisfied)	29.0	30.7	28.3	29.8	32.5	39.2	41.8	38.7	22.1	30.5	27.1
% 2	25.2	22.9	21.5	22.2	15.8	26.7	16.5	23.9	27.6	18.0	22.3
% 3	30.3	26.6	35.5	38.1	33.3	22.7	25.9	27.6	35.6	34.4	33.8
% 4	7.7	9.4	9.0	5.2	10.8	6.3	5.3	7.4	9.2	10.2	9.3
% 5 (Very satisfied)	7.7	10.4	5.7	4.8	7.5	5.1	10.6	2.5	5.5	7.0	7.6
Mean	2.4	2.5	2.4	2.3	2.5	2.1	2.3	2.1	2.5	2.5	2.5
n	155	192	279	252	120	176	170	163	163	128	885

Table 19 shows the extent to which respondents feel it is important that "Day care programs are available for disabled children." While day care is not rated as important as either health care (i.e., medical care, insurance coverage, etc.) or services in the schools, two-thirds of respondent agree that day care is nonetheless "very important."

In their written comments, a number of parents complained that day care facilities would not accept children with chronic physical or serious developmental disabilities. For example, the parent of a 4-year-old Tulsa County boy with a wide range of disabilities (visual, hearing, mobility, neurological, speech, learning, chronic illness and other) wrote, "[My] son needs nursing assistance because he is on a ventilator — there is no day care that accepts him." Similarly, the mother of an 8-year-old Marshall County girl with visual and mobility impairments stated, "Day care won't take handicapped children — excuse was no room yet weekly accounts of new children in local paper." The mother of a 9-year-old Oklahoma County boy with mental retardation wrote,

> I am the parent of a 9 yr. old son with 'Down Syndrome.' The issues which I have struggled with involve Day Care and education. We have seen discrimination problems from Day Care centers and even within the "before and aftercare" programs at the public school which he has attended for 2 years. As a parent, I have had to fight for his rights. And in the end, he was accepted into the day care program. But at what cost? When will this kind of discrimination end? Especially with so called "educated" individuals! When it comes to my son, I am not afraid of a fight. But, I won't be around forever. My hope is that day by day we can

> overcome these issues. And when my son becomes an adult, he can find a meaningful job, something other than [emptying] trash & cleaning up after "normal" people. That he can be as accepted in daily life as he is within his family. I hope this survey is of some help. Good luck! My baby boy deserves everything you can do.

Meanwhile, the mother of a 2-year-old girl with Down Syndrome in Tulsa County opted to keep her child at home because she was fearful for what might happen in day care. She wrote,

> I stay at home w/ her [my daughter] because I'm worried about the treatment she would receive at a day care. But in my staying home I personally think it helped her [develop] faster. I'm always working w/ her (& my other kids do too!) & finding new ways to help [her] grow developmentally. She walked at 1½ yrs. Obviously I'm overwhelmingly proud of her.

Several respondents noted the limited extracurricular and after-school programs for children with disabilities. For example, the parent of an 18-year-old woman with mental retardation wrote,

> I have fought for child care for handicapped children for years. Schools offer it to normal children but frequently refuse it for the handicapped. Desperate need for post high school programs.

Likewise, the mother of a 10-year-old Del City boy with a wide range of disabilities (visual, mobility, speech, and mental retardation) complained that "After school activities are not offered to special education kids unless they have a buddy to help them." The single mother of a 1-year-old daughter with mental retardation wrote, "I would love to have a child care center specializing in 'special needs,' but where is the funding?"

Vocational Rehabilitation

Table 20
Responses:
Vocational rehabilitation provides disabled individuals with the training they need to obtain meaningful employment

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.1	3.3	2.7	2.2	2.3	2.4	1.1	1.2	3.3	3.5	3.0
% 2	2.3	1.4	0.7	1.1	0.8	0.0	1.1	0.0	1.1	0.7	1.0
% 3	0.6	5.2	4.3	6.3	4.5	5.3	3.8	4.1	5.5	7.1	4.8
% 4	9.1	11.8	12.3	13.7	11.4	13.8	12.5	15.8	15.9	10.6	13.7
% 5 (Very important)	86.9	78.2	80.0	76.7	81.1	78.2	81.5	78.9	74.2	78.0	77.6
Mean	4.8	4.6	4.7	4.6	4.7	4.6	4.7	4.7	4.6	4.6	4.6
n	176	211	300	270	132	188	184	171	182	141	989
% 1 (Not satisfied)	23.5	26.0	23.5	30.2	35.8	27.1	31.2	29.9	26.0	27.0	24.7
% 2	21.7	20.3	18.1	16.1	17.1	19.2	21.8	25.5	18.9	13.9	18.7
% 3	31.3	25.0	36.8	37.3	30.9	39.0	30.6	33.1	37.9	40.2	35.1
% 4	10.8	12.0	10.5	9.8	8.1	6.8	6.5	7.0	10.7	9.8	11.6
% 5 (Very satisfied)	12.7	16.7	11.2	6.7	8.1	7.9	10.0	4.5	6.5	9.0	10.0
Mean	2.7	2.7	2.7	2.5	2.4	2.5	2.4	2.3	2.5	2.6	2.6
n	166	192	277	255	123	177	170	157	169	122	890

Vocational rehabilitation services are of concern to many ODS respondents. (See Table 20.) While 78% of respondents rated this need as "very important," individuals with visual impairments (or those who filled out the survey on their behalf) assigned it even greater importance. Respondents' comments concerning vocational rehabilitation (23 of whom volunteered written feedback) were overwhelmingly negative, especially with regard to preparation for meaningful employment.[21] The close relative of an unemployed 33-year-old woman with a variety of disabilities (hearing, neurological, psychological, and chronic illness) wrote, "Voc Rehab is really, really terrible." A 60-year-old man in much the same situation stated, "It's a joke."

---

21. Vocational Rehabilitation programs offered by the Division of Vocational Rehabilitation and the Division of Visual Services help Oklahomans with disabilities get jobs in the careers they choose. DVR and DVS are divisions of the Oklahoma Department of Rehabilitation Services (DRS). Individuals are eligible for vocational rehabilitation (VR) services if they have a physical or mental disability that keeps them from working and need vocational rehabilitation services to prepare them to find, keep or return to employment. Services available through VR include job training, counseling and guidance with job placement. Many of these services compensate for, correct or prevent disability-based barriers to employment (Oklahoma Department of Rehabilitation Services 2002).

A number of respondents expressed frustration that vocational rehabilitation was not in tune with the needs of individuals with disabilities. The parent of a non-employed[22] 20-year-old woman with several disabilities (hearing, mobility, neurological, speech and mental retardation) asserted that vocational rehabilitation failed to provide adequate job training "for multi-disabled who [cannot] work full time." Similarly, the parent of a 22-year-old woman with multiple disabilities (visual, mobility, neurological, psychological, speech, mental retardation and other) wrote, "The state rehabilitation services do not prepare autistic children for life after school." The need for earlier training is especially acute, as the parent of a 17-year-old man with mental retardation explained:

> There is a 'void' and gap in the training for the mentally retarded in high school. School districts provide 'job sampling' and 'skills for the workplace training' only VoTech Center doesn't take MR [mentally retarded] students. "Gap" in where to go for training. Vocational Rehab waits till last year of high school then basically sends all students to workshops in the MR category.[23]

The close relative of an unemployed 19-year-old man with mental retardation and a learning disability expressed a similar concern:

> I was displeased when he graduated from high school, I thought he was to be helped in gaining employment; I was told he had been signed up for a job, which was a lie in the end, and now I'm still trying to help which is not good, is it who you know? .... We had good service from "the Millet Learning Center" in Saginaw, Mich. I have been told you offer excellent help for the [handicapped], but apparently I did not find it.

Two respondents felt that their vocational rehabilitation counselors seemed ill at ease around deaf people. For example, one respondent wrote,

> Vocational Rehabilitation [counselor] was not very helpful initially. He was very ill at ease (for lack of better words) with a deaf person. He lacked any experience with deaf people and I feel we might have missed some additional information.

---

[22] "Non-employed" refers to those who are not working and not seeking work. "Unemployed" refers to those who are not working and currently seeking work.

[23] "Supported employment services are intended for individuals with the most severe disabilities who require a great deal of support to find, learn and/or keep a job. Many individuals who have never worked before or have never worked successfully are able to function well in competitive employment with assistance provided by community-based rehabilitation providers. Individuals with mental retardation, serious mental illness, acquired brain injury, deaf-blindness and other severe disabilities have been assisted to work successfully through supported employment services. ... The primary sources of funding for supported employment services are the Oklahoma Department of Rehabilitation Services (DRS) and the Developmental Disabilities Services Division (DDSD) of the Department of Human Services. These agencies may purchase supported employment services for their clients" (Oklahoma Commission for Rehabilitation Services 2001: 138).

Another (a 26-year-old man with a clerical job) wrote,

> TSHA PW (Project with Industry) and VR counselors need to have lots of improvement in how they work with deaf people. They look like they don't have any idea what problems that are related to deafness and what problems that aren't related to deafness.

Despite these negative comments, a number of respondents did express gratitude for the adaptive equipment and the educational support they received from vocational rehabilitation. For example, a 57-year-old woman with a variety of disabilities (hearing, neurological, and psychological) wrote, "Have been working with vocational rehab — they bought me hearing aids and new glasses. We are so thankful for these services." Similarly, a 52-year-old woman with a hearing impairment wrote,

> Several years ago, my audiologist put me in touch with vocational rehabilitation, through them my qualify of life changed. I was given the opportunity to get hearing-aids [and] eye-glasses. The biggest boost to my self-esteem was going back to school and furthering my education. Although, I didn't finish my education due to getting married, vocational rehabilitation and Tulsa speech and hearing association were very positive experiences. I might be somewhat deaf, but not dumb — thanks to vocational rehab and Tulsa Speech and Hearing!

A 41-year-old man with a neurological impairment praised the state for providing good support for college preparatory training:

> We are all blessed to live in the U.S. The gov./state provide good, adequate help for those w/ a disability. With the desire to go to college, the state does...superior work. They provide all [the necessities] to graduate.

This same respondent felt that there was less support after college, however. Meanwhile, several individuals with more serious developmental disabilities seemed uncertain about the higher education opportunities available to them. A few wrote on the questionnaire to ask whether such opportunities existed.

Several respondents stressed the need for vocational support for *employed* individuals with disabilities. Specifically, assistance with transportation was mentioned several times. A 52-year-old female professional with mobility and neurological disabilities wrote,

> If you are employed and fall between guidelines for help with very needed adaptive equipment, you are out of luck. Voc Rehab helped equip a van that I have kept running for 21 years. I can't afford to pay for a new vehicle and the adaptive equipment but I can't get help. Without it, I can't work.

Likewise, a 69-year-old woman working part-time with a chronic illness wrote,

> When I can work — the only work available to me is contract labor. At the present time I have to borrow a vehicle or pay someone to take me to deliver my finished work and pick up more work to do — My vehicle is minus a transmission and so far [I] haven't found any agency that will help me get it fixed.

A few respondents expressed their disappointment with the parental income threshold for college assistance. These respondents feel that *all* individuals with disabilities should receive these benefits, regardless of their family income. For example, a 51-year-old man earning over $60,000 suggested "that vocational rehabilitation should pay any child of deaf parents for college tuition even dormitory." Similarly, a 20-year-old man with a hearing impairment complained, "Financial aid for college was denied due to my [parents'] financial status. It should have been evaluated on my disability, not their income."

Career Counseling and Job Placement

Table 21
Responses:
Good career counseling is available for disabled persons

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.1	3.3	3.6	2.9	4.4	4.2	2.1	2.3	4.3	5.6	3.6
% 2	1.7	0.9	1.0	1.8	0.7	0.5	1.1	0.6	1.1	0.0	1.2
% 3	3.4	6.0	6.9	7.2	5.1	6.3	3.7	5.8	7.6	6.3	6.4
% 4	17.9	18.6	14.5	16.3	16.1	20.9	12.3	17.9	16.2	13.2	16.2
% 5 (Very important)	76.0	71.2	74.0	71.7	73.7	68.1	80.7	73.4	70.8	75.0	72.6
Mean	4.7	4.5	4.5	4.5	4.5	4.5	4.7	4.6	4.5	4.5	4.5
n	179	215	304	276	137	191	187	173	185	144	1011
% 1 (Not satisfied)	30.8	28.1	28.3	35.2	40.5	30.5	33.1	31.3	33.3	37.1	29.4
% 2	21.3	22.1	21.9	19.9	21.4	22.0	23.1	23.8	20.1	16.1	21.5
% 3	29.6	28.6	33.0	34.0	23.8	33.9	32.0	34.4	32.8	32.3	33.3
% 4	11.8	10.6	11.5	7.0	7.9	7.9	4.7	6.3	7.5	7.3	8.6
% 5 (Very satisfied)	6.5	10.6	5.4	3.9	6.3	5.6	7.1	4.4	6.3	7.3	7.2
Mean	2.4	2.5	2.4	2.2	2.2	2.4	2.3	2.3	2.3	2.3	2.4
n	169	199	279	256	126	177	169	160	174	124	912

Table 21 shows the importance of career counseling among ODS respondents. While career counseling is less important than many other educational needs, relatively few respondents are satisfied with the services currently available. It is worth mentioning that satisfaction rates vary by the type of disability, since some impairments virtually preclude full-time employment while others have a much more limited impact on occupational opportunities. As one respondent wrote next to the question on career counseling, "This would and must depend on the disability." Even respondents with modest occupational goals feel that better career counseling would be beneficial, however. An unemployed 44-year-old man with several disabilities (mobility, neurological, psychological, speech, learning, mental retardation, and chronic illness) wrote, "There is no help for me to learn numbers and counting and get good job."

Table 22
Responses:
Good job placement help is available from state rehabilitation and employment agencies and from other employment programs

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	2.2	4.6	2.6	4.0	6.0	4.2	3.2	2.9	3.3	4.2	3.6
% 2	1.7	0.9	1.7	2.2	0.8	1.0	0.0	0.6	1.6	1.4	1.2
% 3	2.2	5.6	5.3	6.6	5.3	7.8	6.5	8.7	10.3	5.6	6.2
% 4	13.5	15.3	14.2	16.2	15.8	14.6	12.9	16.8	13.6	12.5	15.6
% 5 (Very important)	80.3	73.6	76.2	71.0	72.2	72.4	77.4	71.1	71.2	76.4	73.4
Mean	4.7	4.5	4.6	4.5	4.5	4.5	4.6	4.5	4.5	4.6	4.5
n	178	216	303	272	133	192	186	173	184	144	1004
% 1 (Not satisfied)	28.5	26.6	26.9	31.1	35.5	25.0	30.1	27.6	31.0	32.5	26.9
% 2	21.2	21.8	21.1	20.5	18.2	23.8	19.3	22.4	17.0	19.2	21.1
% 3	35.2	31.9	35.6	35.0	34.7	39.5	37.3	42.3	37.4	35.0	36.7
% 4	6.1	8.5	8.0	7.5	6.6	7.0	6.0	5.1	7.6	6.7	7.7
% 5 (Very satisfied)	9.1	11.2	8.4	5.9	5.0	4.7	7.2	2.6	7.0	6.7	7.7
Mean	2.5	2.6	2.5	2.4	2.3	2.4	2.4	2.3	2.4	2.4	2.5
n	165	188	275	254	121	172	166	156	171	120	888

With regard to job placement (Table 22), most respondents are unhappy with the limited assistance currently offered. Individuals with mental retardation and/or psychological disabilities (or those who filled out the questionnaires on their behalf) expressed especially high levels of dissatisfaction. In response to this question, an unemployed 44-year-old woman with impaired mobility and difficulty hearing sarcastically wrote, "Yea Right [—] for 10 years I've gone for state jobs & haven't got one." Another respondent, the parent of a non-employed 24-year-old woman with mental retardation, complained that Oklahoma's employment programs had overly strict policies and failed to serve the needs of individuals with disabilities:

> Workshops cater to higher functioning individuals — long waiting list for those lower functioning or in wheelchairs. Workshops have overly strict rules such as no talking, having to stand all day, paid by piecework, if you take time off, expected to pay workshop for days off.

Meanwhile, the parent of a 24-year-old man with a variety of disabilities (neurological, speech, learning and mental retardation) complained that some individuals who were not ready to progress were being pushed out of the workshops:

> The director of our workshop tells us that the State is pushing her to put all individuals out in the work force. In our workshop setting some can work out while others will never be able. I don't understand why you push our workshops to send all of our individuals out. Some will never be able to because of their disabilities. .... As a parent this brings a lot of grief...

While Oklahoma's current job placement services are almost uniformly regarded as ineffective, not all respondents feel that improved or better-funded services would be any *more* successful. A 35-year-old man with AIDS (working ten hours per week in a professional occupation) wrote "Waste of funds!" next to this question.

Employment Opportunities and Obstacles

Table 23
Employment Status of Individuals With Disabilities Aged 18 to 64, by Type of Disability

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
Unemployed[a]	15.6	19.5	15.1	14.5	18.9	13.2	20.5	16.7	11.8	21.2	15.7
Non-employed[b]	54.9	39.8	59.4	56.6	59.5	52.8	50.0	41.7	60.1	54.9	49.4
Employed	29.5	40.6	25.5	29.0	21.6	34.0	29.5	41.7	28.1	23.9	34.8
n	122	133	239	221	111	106	122	120	153	113	743

[a] Not working but currently seeking employment.
[b] Not working but currently *not* seeking employment.

Approximately one-third of working-age Oklahomans with disabilities are currently employed. Individuals with hearing impairments or mental retardation have the highest employment rates, while those with psychological disabilities are the least likely to be working. (See Table 23.) Persons with learning disabilities are most likely to be seeking employment, whereas those with chronic illness are most likely to be outside the labor force (not working and not looking for work).

Table 24
Responses:
A variety of job opportunities are available for disabled persons

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	2.2	3.8	2.6	2.6	2.3	2.6	2.2	1.7	3.3	3.4	3.3
% 2	1.7	0.5	2.3	2.6	1.5	2.6	0.5	0.6	1.6	1.4	1.1
% 3	1.1	4.7	4.0	5.5	5.3	6.3	6.5	7.5	5.4	2.7	4.6
% 4	13.3	14.1	13.2	16.8	16.5	11.5	11.3	14.9	14.7	13.0	15.5
% 5 (Very important)	81.8	77.0	77.9	72.5	74.4	77.1	79.6	75.3	75.0	79.5	75.6
Mean	4.7	4.6	4.6	4.5	4.6	4.6	4.7	4.6	4.6	4.6	4.6
n	181	213	303	273	133	192	186	174	184	146	1003
% 1 (Not satisfied)	47.6	42.7	42.8	39.9	46.8	41.8	43.2	42.2	40.9	46.8	40.1
% 2	24.4	21.9	24.3	22.1	23.0	25.4	23.7	26.1	21.6	19.8	22.2
% 3	19.0	20.3	25.7	31.4	22.2	24.9	24.3	27.3	25.7	23.8	26.9
% 4	3.6	7.3	3.6	3.5	4.0	5.1	2.4	3.1	3.5	7.1	5.2
% 5 (Very satisfied)	5.4	7.8	3.6	3.1	4.0	2.8	6.5	1.2	8.2	2.4	5.6
Mean	1.9	2.2	2.0	2.1	2.0	2.0	2.1	2.0	2.2	2.0	2.1
n	168	192	276	258	126	177	169	161	171	126	900

Of all the questions in the survey, those relating to employment generated some of the lowest levels of respondent satisfaction. While respondents overwhelmingly rated job opportunities as "very important," less than 6% were "very satisfied" with the current situation. (See Table 24.) Next to this question, a 53-year-old man with a neurological impairment (the full-time director of a disability services agency) wrote that "unemployment and underemployment [are] rampant."

In their written comments, approximately 1 in 5 respondents (of those who provided written feedback) voiced employment-related concerns. Many survey respondents noted the difficulty of finding paid employment. For example, the parent of a 10-year-old boy with mental retardation and a speech impairment wrote,

> Many young adults end up working at a volunteer job because there are limited resources to help them find adequate employment, especially if they have any health issues, even if they are otherwise capable of holding down a job.

Another parent lamented the fact that his/her 21-year-old daughter was having so much difficulty on the job market due to her mental retardation and related disabilities:

> At this time, we are experiencing a very difficult time finding employment for Lori [daughter]. She has followed all the available resources in the past but always seems to eventually be out of work. She is capable but once she meets the criteria with the job coach it seems that is the time that she gets herself in a situation that she cannot handle (on the job) and therefore loses her employment. I am now wondering how much good her high school education did her. .... She is very capable and every day that goes by that she does not use the abilities that she has she reverts back to [an] even younger child than she is.

Likewise, an unemployed 48-year-old woman with a psychological disability and chronic illness complained that job placements for individuals with disabilities were frequently incongruent with their educational qualifications:

> Places such as Thunderbird Club House that help employ those with mental disabilities only find blue collar work even if you have a graduate or college degree this seems totally unfair.

Several respondents described how their disabilities put them at a disadvantage in the job market, and many complained that there were simply not enough appropriate jobs available for individuals with disabilities who wanted to work. A 31-year-old man with a chronic illness (currently not working, but receiving worker's compensation) wrote, "More options need to be available for people with disabilities....jobs suitable for the individual." Similarly, a non-employed 51-year-old female with a hearing impairment and a chronic illness reported,

> I can only work on "good days," saying I can work and finding someone who will hire me are two different things. Pro-rating for parttime might help, except I never know when my "bad days" will strike.

Many individuals with disabilities would like to work but find that their physical impairments simply make this impossible. A 41-year-old woman with hearing and learning disabilities reported that ear problems, dyslexia, and anxiety attacks keep her from finding or keeping a job. Likewise, a non-employed 57-year-old woman with a variety of disabilities (hearing, neurological, psychological and a seizure disorder) wrote, "I have tried to work and have seizures on the job. ..... I would work if I could."

Table 25
Responses:
Employers have a positive attitude about hiring people with disabilities

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.1	2.3	2.7	2.6	0.7	3.7	2.1	1.2	3.8	2.7	3.0
% 2	1.7	0.5	0.7	2.2	1.5	1.0	1.1	1.7	0.5	0.7	1.3
% 3	1.1	3.7	2.7	4.1	3.0	2.6	2.1	2.9	3.2	3.4	3.3
% 4	9.9	13.9	10.7	14.0	14.9	11.5	11.7	14.5	13.4	10.1	12.5
% 5 (Very important)	86.2	79.6	83.2	77.1	79.9	81.2	83.0	79.8	79.0	83.2	79.9
Mean	4.8	4.7	4.7	4.6	4.7	4.7	4.7	4.7	4.6	4.7	4.7
n	181	216	298	271	134	191	188	173	186	149	1002
% 1 (Not satisfied)	42.0	38.5	43.6	39.8	50.0	35.1	38.8	31.4	45.1	44.6	39.3
% 2	26.6	25.1	23.6	25.8	23.0	27.6	28.2	34.6	26.9	22.3	25.7
% 3	23.7	24.1	24.7	27.0	19.8	27.6	22.9	28.3	17.1	24.6	25.4
% 4	4.1	6.7	5.8	5.1	3.2	7.5	4.7	4.4	6.3	4.6	6.0
% 5 (Very satisfied)	3.6	5.6	2.2	2.3	4.0	2.3	5.3	1.3	4.6	3.8	3.5
Mean	2.0	2.2	2.0	2.0	1.9	2.1	2.1	2.1	2.0	2.0	2.1
n	169	195	275	256	126	174	170	159	175	130	905

Table 25 shows the extent to which respondents felt it was important that "employers have a positive attitude about hiring people with disabilities." While 80% of respondents characterized this need as "very important," only a tiny minority felt that employers do indeed have positive attitudes. In fact, this single question generated the lowest levels of satisfaction of all the 56 needs-related statements included in the survey. Expressing the disillusionment felt by many individuals with disabilities, one 47-year-old woman wrote, "I've been unable to work since Feb. 1997. I have applied and been turned down so many times already." Likewise, an unemployed 59-year-old man with multiple disabilities stated, "I have been [discriminated against by] age and [disability]. I have been [turned] down for jobs when I got to a place where I could work."

A number of respondents complained of widespread job discrimination. A 48-year-old service employee with a hearing impairment summed up the sentiments of many respondents when she wrote, "There needs to be a lot of work done about employment and discrimination in the work hiring process." Similarly, a 22-year-old clerical worker with a learning disability stated,

> I have found that many people still fear people with disabilities, mostly physical. These fine people are not given a fair shake & are often given non-thinking jobs when they are capable of much more. I could go on forever about lack of respect, but I will save you the drill.

Knowing the challenges her 11-year-old son was likely to face, one respondent wrote, "Look around, do you really seem very many disabled people in the work place [?]"

Several respondents provided detailed sketches of how they had been run out of their jobs or denied employment because of their disabilities. An unemployed 34-year-old woman with a learning disability wrote,

> Yes, I have [a lot] of problems. .... here [in] the small town of Stroud, I have put [in an] application in the nursing home here, they [won't] hire me but, she hires others. ... I don't think it's fair, that she does that. Is there way I can take this woman to court, for discrimination, against a handicapped adult who has L.D. and [is] slow, but can learn.

An unemployed 21-year-old man pointed out that discrimination can occur both in hiring and on the job:

> I...work as a screenprinter. I believe my time was taken advantage of with no overtime. I was always blamed for mistakes (How easy it was to point the finger at the deaf guy). I then quit in November of 2000. I've been trying to find work as an artist but have been rejected. I believe the rejection is due to discrimination. I believe that these companies don't want someone like myself because they fear that we will mess something up or cause them problems. All this because of a hearing defect. Why? I've been searching for that answer a long time.

The notion that employers do not want to hire individuals with disabilities was voiced by individuals with both physical and mental disabilities. For example, an unemployed 49-year-old woman with a psychological impairment wrote,

> Employers do not like [to] employ people like myself with (By Polar) [sic]. Every time they find out what...all the [medicines] I take for my mental (Bypolar) [sic] they refuse [to] even give me [a] job. People look at people like me like they are (crazy) and couldn't even find [their] ass. That's the way they treat me. Wherever I move, I still can't locate any work. Or even give me any chances [to] prove I can do the work. Being mentally disabled is an everyday hassle for itself in everyday living. At least it is for me.

Another respondent, an unemployed 37-year-old man with both mobility and psychological disabilities, chronicled his struggles on the job front:

> I lost my left knee in line of duty. I also have P.T.S.D. [post-traumatic stress disorder]. When I was [laid] off my job of 8 yrs I went for another interview. They sent me for my physical and drug test. A question on the paperwork asked any meds. taken in 7 yrs. Two yrs. ago I was on [Xanax]. My drug test came back clean but the P.A. said he couldn't [recommend] me for the job because: (1) I had taken the [Xanax] and it didn't matter when. (2) He told me that P.T.S.D. was just one step below being full blown crazy. So I didn't get the job. I tried to get something done but you [can't] get any help in Okla. It's a shame I was born in Atoka, Oklahoma. And this is the worst state to get any help in!! I still [can't] get a job.

A non-employed 48-year-old man with psychological and learning disabilities described a similar situation:

> I worked for the Federal Government until Sept. 2000 (25 years). It was hell to have to put up with having to prove job failure that resulted from mental disability. All confidence was shattered, and there was no assistance available to be evaluated on the basis of vocational assessment. The way I was treated and documented as a bad [employee] took away from having faith in the vocational concerns. I left feeling incompetent, a "problem" employee and that I'd never be trusted again. A year later I still don't feel I'm capable of working — the fact that manic depression, [obsessive] compulsive disorder, and attention deficit disorder came out really bad after I had been very ill and could not work for six months from 1998-1999, came out as my supervisor got rid of me rather than allowed me more time to recover. I went from an income of close to $60,000 to barely $25,000 for the yr. 2001, and about $14,000 yr beginning in 2002... When I lost my job/'retired on disability', I lost my income...and my family.

Not only were prospective employers reluctant to hire individuals with disabilities, but several respondents also complained that employers were unwilling to provide "reasonable accommodations" as mandated by the 1990 Americans with Disabilities Act (ADA). For example, in describing the job market, an unemployed 42-year-old woman with a variety of disabilities (mobility, neurological, chronic illness and other) complained that there were "limited [opportunities] or respect of ADA rights." The personal caregiver of a non-employed 58-year-old woman with a neurological disability wrote,

> Willingness to discuss and even make reasonable [accommodations] depends on the politics of the area. With the advent of [cubicles] many do not allow room for a wheelchair or scooter. Rather than even working with people on accommodations they are threatened with being "released" or going out on disability. Without the time and money to go into lengthy legal litigation the common worker doesn't stand a chance.

Likewise, an unemployed 48-year-old respondent revealed how requests for reasonable accommodation can have negative results:

> I was a highly skilled computer scientist who was laid off less than 1 year after asking for reasonable accommodation. I had 20 years [of] experience, and was only 18 months away from early retirement with great benefits. Now, I have nothing, and no one will hire a 48 yr old computer scientist who is legally blind. ... My unemployment runs out in 3 weeks — let me ask you, what do I do now?

A similar situation was reported by one 46-year-old man with neurological and mobility impairments. He wrote,

> Just briefly recap my situation. I went on disability in January 1995 due mainly to the fact that the company I worked for did not want to [accommodate] me. I had started using an electric cart and had to disassemble it to load in the trunk of my company car. I was the District Manager in Oklahoma for a metal distribution company. Most of my time was spent in the office but [I] did make calls with the outside salesmen. I asked for a van to make loading and unloading [easier] but the company did not think it was a fair and [reasonable]

> request. Even with the ADA in force I could not get any help from them, so I [chose] to take disability the company offered not wanting to take a chance of the company letting me go.

Perhaps surprisingly, major public employers such as the University of Oklahoma often decline to participate in programs that promote the employment of individuals with disabilities. An unemployed 39-year-old woman expressed her disappointment:

> When major employers like OU refuse to be employers for ticket to work I give up hope of ever getting off SSDI. OU and OKC community college have both declined to participate in Ticket to Work.[24]

Several respondents described how the system of government benefits is set up in a way that discourages individuals with disabilities from obtaining employment. Some individuals who are perfectly willing to work fear the loss of government benefits that would inevitably result if they earned "too much" income. For example, a non-employed 36-year-old woman with an unspecified disability (family income between $5,000 and $9,999; family size of 2) wrote,

> With what I receive from the government I hardly get by, but I can't work because if I make over $40 month I will lose my SSI. My SSI is what helps me get my [Medicaid]. This is what pays for my medicine. My medicine is $500 a month. On a minimum wage I couldn't afford [the medicine]. I am between a rock and a hard place. What I am trying to say is I want to work but can't for fear of losing benefits.

---

[24] Under Oklahoma's Ticket to Work program, the Social Security Administration distributes tickets to over 100,000 disabled SSDI and SSI recipients between the ages of 18 and 64. "The tickets can be used to purchase services from service providers called employment networks which will provide employment assistance, vocational rehabilitation services and other support services. The Department of Rehabilitation Services' (DRS's) divisions of Vocational Rehabilitation and Visual Services will form a primary employment network with links to more than 50 partners under contract to provide services throughout the state" (Oklahoma Department of Rehabilitation Services 2002).

Another respondent echoed these sentiments:

> I have a son who has a head injury and is unable to work (hold down a job). There is no type of help for him to have activities, make his life to have a purpose, like some type of small job and not get penalized on his SSDI — no assistance for housing, food, the government will give all kinds of help to the retarded people, but not head injury people. This is a sad world we live in.

Transportation

Table 26
Responses:
Public transportation allows individuals with disabilities to go where they need to go

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	4.1	7.9	4.0	2.8	4.3	5.5	4.7	4.4	2.6	2.7	4.6
% 2	0.5	1.3	0.9	2.1	1.4	0.0	0.0	1.1	2.6	1.3	1.5
% 3	4.7	5.3	5.8	8.4	7.2	5.5	6.3	8.2	8.8	4.7	6.3
% 4	10.4	17.6	15.1	14.7	11.5	18.9	14.1	13.1	13.5	10.1	13.9
% 5 (Very important)	80.3	67.8	74.2	72.0	75.5	70.1	74.9	73.2	72.5	81.2	73.6
Mean	4.6	4.4	4.5	4.5	4.5	4.5	4.5	4.5	4.5	4.7	4.5
n	193	227	325	286	139	201	191	183	193	149	1042
% 1 (Not satisfied)	28.7	21.8	25.4	23.7	28.0	24.0	27.1	25.3	24.7	25.7	22.6
% 2	19.3	15.8	23.1	20.7	12.8	20.1	18.8	16.3	19.5	14.0	19.0
% 3	29.8	32.2	32.2	37.2	29.6	30.7	28.8	34.9	32.8	35.3	33.4
% 4	9.9	15.8	9.1	10.2	14.4	16.2	12.4	15.7	13.8	8.1	12.8
% 5 (Very satisfied)	12.2	14.4	10.1	8.3	15.2	8.9	12.9	7.8	9.2	16.9	12.2
Mean	2.6	2.9	2.6	2.6	2.8	2.7	2.7	2.6	2.6	2.8	2.7
n	181	202	307	266	125	179	170	166	174	136	946

Table 27
Responses:
Public transportation (for disabled individuals) operates during convenient hours

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	5.9	8.6	4.7	4.3	4.4	5.6	4.8	4.5	2.1	3.4	5.1
% 2	0.0	2.3	0.6	1.1	2.2	0.5	0.5	1.1	3.2	1.4	1.8
% 3	8.1	8.6	7.0	11.0	7.3	6.6	8.5	9.6	9.5	4.1	8.9
% 4	11.4	16.7	18.0	18.9	15.3	19.2	13.2	15.2	16.4	13.7	16.0
% 5 (Very important)	74.6	63.8	69.6	64.8	70.8	68.2	73.0	69.7	68.8	77.4	68.2
Mean	4.5	4.2	4.5	4.4	4.5	4.4	4.5	4.4	4.7	4.6	4.4
n	185	221	316	281	137	198	189	178	189	146	1023
% 1 (Not satisfied)	31.8	24.4	27.5	26.7	30.6	24.7	29.8	30.4	32.7	31.3	25.3
% 2	25.3	16.1	26.8	23.7	16.1	24.2	19.3	18.0	15.2	16.0	19.3
% 3	24.7	34.2	28.1	32.4	30.6	31.5	31.6	35.4	31.0	31.3	33.1
% 4	7.6	11.4	9.2	9.9	9.7	11.8	9.4	8.1	12.9	7.6	11.7
% 5 (Very satisfied)	10.6	14.0	8.5	7.3	12.9	7.9	9.9	8.1	8.2	13.7	10.6
Mean	2.4	2.7	2.4	2.5	2.6	2.5	2.5	2.5	2.5	2.6	2.6
n	170	193	295	262	124	178	171	161	171	131	916

Tables 26 and 27 show the importance of public transportation among ODS respondents. While a large majority of respondents rated public transportation as "very important," it is clearly not as critical as health-care services, educational opportunities, or employment. There is little variation in responses by type of disability, although individuals with hearing impairments are somewhat less concerned and somewhat more satisfied than the other ODS respondents.

In their written comments, 30 respondents (6.6% of those providing written feedback) voiced concerns about the lack of a good public transportation system in Oklahoma. For instance, the parent of a 9-year-old Oklahoma County boy with multiple disabilities (visual, hearing, speech and mental retardation) stated that "transportation and housing issues continue to be barriers for persons with disabilities to live in communities." The close relative of a 24-year-old woman with several disabilities wrote, "Public places and transportation should always be affordable & open for people with disabilities."

A number of respondents, particularly those living in rural areas, noted that public transportation was unavailable where they lived, and several voiced a need for more affordable transit services. For example, a non-employed 39-year-old woman with a neurological disability wrote,

> I have been told seeing as I live in Norman rural area, I have no hope of transportation. I also have no hope of sidewalks or even shoulders on streets to walk on. .... Why does Norman, Okla., a small metro city of over 98,000 citizens have NO public transportation??? There has to be more than one disabled person in Norman. I have been speaking with the city of Norman before and have been told to ask a Church for help w/ transportation. My answer being "I get more help from my Church in Norman than I get from the city of Norman." I also think it is about time to start paying my city taxes to my Church.

The parent of a 19-year-old Pittsburg County woman with a visual impairment described a similar quandary:

> She [my daughter] lives 4 miles from the college; the Tulsa transit stops 2 miles from the college and Broken Arrow transit stops 2 miles before the college. Neither will cross the line to get her to school and the college doesn't provide a bus. <u>Transportation</u> is the hardest of all to be [independent] as a [handicapped] person.

As might be expected, ODS respondents pointed out quite a few underserved regions within the state. A non-employed 54-year-old woman with a chronic illness wrote, "One of our biggest concerns here in McAlester is the lack of good & convenient public transportation." Similarly, a non-employed 40-year-old Muskogee County man with several disabilities (visual, hearing, mobility and chronic illness) reported, "Our transit services runs two buses and does not pass near my house."

Several respondents noted that existing services should be more user-friendly and better publicized. For instance, the parent of a non-employed 24-year-old woman with mental retardation wrote, "Transportation major issue. Public transportation too intimidating even where available. Recommend personalized, individual transportation be made available and publicized." Respondents also complained that public transportation is inconvenient (time-consuming) and that it seldom lets individuals go where they want, when they want (or need) to go. The parent of a 13-year-old boy with multiple disabilities wrote about public transportation in Tulsa County, "Even with public transportation it is still difficult to get around without spending hours riding, walking and waiting on busses. It has been very frustrating and still is." A 50-year-old Jackson County woman simply stated, "It's too slow."

Many disabled Oklahomans are especially dependent on public transportation to get to and from their places of employment. Similarly, many have no other way of getting to their doctors' offices. An employed, 50-year-old Oklahoma County man with a chronic illness wrote, "Need free transportation to & from work for disabled people who work irregular hours." The close relative of an unemployed 18-year-old woman with a variety of disabilities gave a similar opinion: "I feel that people with disabilities should have free transportation to home from work." Stressing the link between transportation and health care, an unemployed 62-year-old woman with multiple disabilities expressed a need for "Transportation to medical appts in Bartlesville especially to Tulsa to <u>better</u> <u>doctors</u>."

Several respondents also complained that public transportation seldom allows individuals with disabilities to participate in social or recreational activities. For example, the parent of a non-employed 20-year-old with a variety of disabilities (hearing, mobility, neurological, speech, and mental retardation) wrote,

> A disabled person cannot live a spontaneous life, as can an able-bodied, for transportation access is so limited; often must be reserved 24 to 48 hours ahead — and none on Sundays. Able-bodied people would not tolerate the inability to not be able to decide each day what to

> do — persons w/ disabilities can't decide — 'Hey let's go out to a movie, or let's go to the park' when they feel like it — Because of no Sunday public transportation, persons with disabilities are sorely restricted from exercising their freedom to [worship] on Sundays, or work, or have any activity outside the home on Sunday.

The parent of a non-employed 44-year-old woman with mobility and neurological disabilities in Comanche County wrote,

> The city I live in, Lawton, Ok., has no provision for transportation for wheelchair users. There is a Medvan operated by "Meet the Needs," a non-profit group for Dr. appointments if you call 24 hrs. in advance. There are no provisions for shopping or recreation transportation.

Meanwhile, a 64-year-old woman with a variety of disabilities (visual, hearing, mobility and chronic illness) who lived in Senior Housing in Tulsa County complained about the "carry-on" rules of the public transportation that she participated in:

> Although we appreciate the lift bus transportation and understand why they limit us to one bag or everything we can hold on our lap after we go grocery shopping, the reality of it is that at least once a month we need to stock up on groceries and household products. So the bus does not help that way.

On a positive note, however, one Oklahoma County respondent — the parent of an employed 21-year-old man with multiple disabilities — did indicate that public transportation "is improving."

Handicapped Parking

Table 28
Responses:
Handicapped parking ordinances are strictly enforced

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.6	5.7	0.3	0.7	1.5	3.0	2.1	3.3	2.1	0.7	2.8
% 2	0.5	2.2	0.6	2.8	2.9	0.5	1.0	1.1	1.0	0.7	1.4
% 3	4.8	6.1	5.8	5.2	8.8	5.9	6.7	7.8	5.2	6.2	6.3
% 4	14.8	20.4	11.0	18.5	12.4	16.3	12.4	15.6	16.1	11.7	15.0
% 5 (Very important)	78.3	65.7	82.3	72.8	74.5	74.3	77.7	72.2	75.5	80.7	74.5
Mean	4.7	4.4	4.7	4.6	4.6	4.6	4.6	4.5	4.6	4.7	4.6
n	189	230	328	287	137	202	193	180	192	145	1038
% 1 (Not satisfied)	33.0	26.7	34.9	32.4	31.3	31.0	29.5	23.5	25.7	32.6	28.3
% 2	18.4	19.9	18.6	22.4	20.3	21.7	17.6	19.3	23.5	14.1	18.7
% 3	20.7	22.3	23.0	22.4	21.9	23.4	25.6	30.7	26.3	25.2	24.7
% 4	14.5	14.1	14.8	14.0	10.2	12.5	13.1	16.9	14.0	8.1	15.2
% 5 (Very satisfied)	13.4	17.0	8.8	8.8	16.4	11.4	14.2	9.6	10.6	20.0	13.1
Mean	2.6	2.7	2.4	2.4	2.6	2.5	2.6	2.7	2.6	2.7	2.7
n	179	206	318	272	128	184	176	166	179	135	961

The enforcement of handicapped parking regulations is of great importance to nearly two-thirds of ODS respondents. (See Table 28.) Predictably, individuals with mobility impairments — many of them wheelchair users — ranked this need as especially important.

As might be expected, most of the written survey comments were from mobility-impaired individuals as well. For example, a 49-year-old man who relied on a wheelchair wrote, "Parking is [rarely] enforced in this state. Perhaps if there was a bill or condition that would be adopted to use the handicapped and their families that could issue citations on those people and/or vehicles." The close relative of a 73-year-old woman with a neurological disability expressed a "need to enforce handicap parking more strictly," just as a 34-year-old woman with a neurological disability wrote, "I also had a lot of problems with people in our old apartment complex who constantly parked in the handicap spots and management who didn't want to do anything about it." Likewise, the personal caregiver of a 58-year-old woman with a neurological disability wrote,

> There is a total lack of enforcement and education in this area. In many areas, spots not always clearly marked, people always parking in the hash marks for side entrance vehicles, people still parking with expired [placards], paper (really old) waivers, always driving with the [placards] hanging on the mirror, etc. While on this subject, just ride with us for one day using a side-entry vehicle or chair. As a side point of interest, after spending several days at a local hospital and going outside several times during the day I was totally amazed by the number of staff volunteers/employees who used the accessible parking near the entrances to park all day during peak hours when patients are trying to come & go for appointments.

A 64-year-old woman with a variety of disabilities (visual, hearing, mobility and chronic illness) voiced a similar complaint:

> Handicap parking is not at all enforced at medical facilities, stores like Wal Mark, K-Mart, Ware House Market, gas stations, schools, libraries. During holidays and bad weather if someone takes [the spots], it's even worse. Gas stations & some large business places have handicap parking but it's at the far end of the building, or, like at some large buildings, it's quite a ways away from the building and difficult to use a wheelchair or walking especially during nasty weather.

A 53-year-old Garfield County man with impaired mobility and a neurological disability wrote, "I have trouble with handicapped parking places not being as per the ADA guidelines. Few have access aisles or elevated signs. I have a very difficult time trying to get businesses to stripe and mark these parking places properly." In a similar vein, a 36-year-old man with a mobility impairment expressed his concern that "there are not enough handicapped parking spaces at most businesses. Some businesses or police do not care or ticket individuals that don't have a handicap decal."

Several respondents felt that handicapped parking permits were too easy to get — that nondisabled individuals were obtaining permits and unfairly taking up handicapped parking spaces. For instance, a

59-year-old man with a variety of disabilities (mobility, neurological, and psychological) wrote,

> Handicapped placards are issued like they are free to anyone who asks. I see people using them who jump out of cars & run to the stores. I see the spaces full but no one sitting (resting), using canes, wheelchairs, etc. No questions asked, no enforcement in parking lots. No truly (few) accessible 'van only' lifts with sufficient space for egress and regress of a wheelchair. I use an electric wheelchair with only the use of my right hand and I get very, very very upset (pissed off) at the fraudulent use of parking & access to bldgs. I complain to the manger/owner to no avail.

Likewise, the close relative of an individual with a disability (who had passed away) wrote, "The only problem I have seen is @ the FAA individuals have requested & received handicap parking & really have no need for it. They had a time when it was required or a spouse but they no longer require the space but still use it so they can park close to the building — need tighter restrictions!" A 65-year-old woman with a chronic illness wrote, "My problem is COPD [Chronic Obstructive Pulmonary Disease] — I often cannot get the handicapped parking, as they don't have enough spaces or the person parked there has a questionable disability — or the parking is [inconvenient]."

Meanwhile, a 66-year-old woman with a mobility impairment pointed out the importance of recognizing that individuals may be in need of handicapped parking permits even if they don't have a clearly visible physical disability. She wrote, "People should stop judging those with handicap permits who look normal. They don't know or see the handicap."

The Americans with Disabilities Act and Accessibility in Public Places

Table 29
Responses:
There is strict enforcement of the Americans with Disabilities Act

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.1	2.2	1.2	1.4	0.7	2.0	1.0	2.3	2.1	1.4	1.9
% 2	0.5	1.3	0.6	2.1	1.5	1.0	0.5	1.1	1.1	0.7	1.2
% 3	6.6	6.7	6.9	8.1	5.1	7.0	6.3	8.0	7.4	6.3	6.9
% 4	9.3	15.2	14.6	17.0	13.1	14.1	13.6	13.6	14.9	11.2	15.9
% 5 (Very important)	82.4	74.6	76.6	71.4	79.6	75.9	78.5	75.0	74.5	80.4	74.1
Mean	4.7	4.6	4.6	4.5	4.7	4.6	4.7	4.6	4.6	4.7	4.6
n	182	224	321	283	137	199	191	176	188	143	1025
% 1 (Not satisfied)	25.7	25.9	28.9	27.0	31.5	26.8	29.1	22.8	22.9	30.5	25.7
% 2	22.8	18.0	22.3	23.2	25.2	21.2	18.6	16.5	21.7	13.7	19.5
% 3	28.1	30.2	31.1	31.1	20.5	34.1	29.1	43.0	29.7	33.6	32.6
% 4	14.0	10.7	12.1	13.9	10.2	11.7	14.0	15.2	17.7	13.7	14.1
% 5 (Very satisfied)	9.4	15.1	5.6	4.9	12.6	6.1	9.3	2.5	8.0	8.4	8.1
Mean	2.6	2.7	2.4	2.5	2.5	2.5	2.6	2.6	2.7	2.6	2.6
n	171	205	305	267	127	179	172	158	175	131	942

Although 74% of ODS respondents feel that strict enforcement of the Americans with Disabilities Act (ADA) is "very important," fewer than 25% are satisfied with the current situation. (See Table 29.) In fact, quite a few respondents remarked that ADA violations are commonplace. "Our own hospital in El Reno does not conform to the ADA," wrote a 49-year-old man with mobility and psychological disabilities. A 40-year-old man with a multiple impairments (visual, hearing, mobility and chronic illness) declared that "ADA and handicap laws are a joke in Muskogee." Likewise, a 50-year-old man with a neurological disability wrote, "Making businesses and places compliant with ADA is great, however there [are] too many different interpretations of compliance."

While insufficient handicapped parking was the most commonly mentioned accessibility concern, respondents also expressed dissatisfaction with inaccessible sidewalks, shopping centers, restaurants, housing, and playgrounds. For example, a number of respondents, particularly those who relied on scooters or wheelchairs, reported considerable difficulty getting around outdoors because of the lack of curb cuts. A 67-year-old man who relied on a motorized wheelchair wrote, "My pet gripe is the lack of [sidewalks] & ramps on curbs." Likewise, a 68-year-old man with hearing and mobility impairments wrote,

> Many shopping places do not have handicapped ramps available for electric and manual wheelchair and electric scooters. Lots of stores don't have enough aisle space for the wheelchairs or electric scooters.

A 49-year-old man with multiple disabilities (hearing, mobility, and speech) described how he had witnessed a man fall due to the lack of a curb cut. His subsequent complaint brought no changes.

> By the way — I witnessed a man with advanced Lou [Gehrig's] on the street — glasses and wheelchair laying away from his prone form — because a curb caused him to fall. <u>No</u> <u>ramp</u> to mailboxes! (Also no ramp in front of office — just a cement curb) I reported this to the office [Welcome Home Mobil Home Park] & told them the man had quite a gash on his head — that was over 2 weeks ago and <u>no</u> <u>changes</u> have been made in the curb yet! Heaven only knows how long the man lay there! It was dusk! He could have been run over!

The absence of ramps at public buildings was mentioned by several respondents, who also pointed out that many ramps are not suitable for individuals in wheelchairs. For example, a 45-year-old Pontotoc County woman with mobility and neurological disabilities wrote,

> People who build ramps should try using them — some are foolishly [too] steep & dangerous. What are we to do when there is no one to assist us? We don't go or do what we want, cause unable to.

Several respondents also mentioned that many grocery stores and shopping malls — in particular, their restrooms — are not wheelchair-accessible. A 73-year-old woman with a neurological disability wrote,

> Malls are not very [accessible] to handicapped people. There are not enough elevators to transport wheelchairs. Parking spaces for the handicapped are far away from the entrances. Grocery stores don't have wide enough aisles for handicapped people and do not have items in the meat sections where I can reach easily. Also, there aren't enough of the electric baskets or regular chairs to [accommodate].

A 41-year-old Comanche County woman with a mobility impairment voiced a similar complaint:

> After surgeries, I had to use the wheelchair. The bathrooms are made for [an] 8-inch wide wheelchair. Doors are hard to open and the handle is [too] high to reach. Behind the bathroom doors are usually trash cans, flower decals or other items, so that the door doesn't open [completely]. The ramps in front doors and stores are too high for a person in wheelchair to push her/himself up the curb. Store doors (Department store entry from streets) opens first [automatically] but the second door has to be opened by hand — what kind of sense that is??? Some [restaurants don't] have enough space between tables to move around the wheelchair. Forget department store to shop for cloth, the cloth racks are so close together that even a 'walking person' can't go through.

The lack of adequate accommodations even extends to voting booths, as a 36-year-old man with a mobility impairment pointed out: "Voting booths are [too] tall for most that are handicapped. Most stores have [aisles] that are [too] close together for a person in a wheelchair and a shopping cart to get past." A 65-year-old woman with a chronic illness complained that the lack of accessibility at commercial buildings also extended to lodging facilities:

> Many programs (community) [offered] to the older person are aimed at the healthy senior citizen (this includes AARP trip (I know they need to [accommodate] those that don't require extra help). Hotels do not have enough ground floor rooms or the rooms are not [conveniently] located.

A surprising number of respondents mentioned the fact that very few playgrounds are accessible to children with disabilities. The mother of an 8-year-old Marshall County girl with visual and mobility impairments expressed her regret that there is virtually "no playground equipment for handicapped children." Another respondent reported, "My school district was 0% accessible equipment on playgrounds, which doesn't meet ADA requirements." Similarly, the parent of a 5-year-old child with a learning disability wrote,

> In Marshall County schools Madill need play ground stuff for disability children very much in need. There is nothing for them to play on but to [sit] in the dirt to play. No swings or any other stuff to play on. And that is not right.

A few respondents also remarked that movie theaters and other entertainment establishments tend to provide wheelchair-accessible seating only in the least desirable locations. A 65-year-old woman with a chronic illness wrote, "Handicap — w/c seating at movie theaters is often too close to the screen, causing neck strain." Similarly, a 56-year-old Jackson County woman with a variety of disabilities (visual, mobility and neurological) wrote, "Auditoriums should be more aware and sensitive and don't place wheelchair bound people to sit in the back and out of the way. We can't see a program or concert if people stand."

Individuals who have bladder problems or difficulty walking are often especially disadvantaged in terms of public accommodations. A 66-year-old woman with breathing problems and a mobility impairment suggested that "chairs or benches should be available in stores/grocery stores at check out, etc., for people who cannot stand very long." Another respondent remarked, "Restrooms should be in more convenient places for those of us with bladder incontinence."

Respondents' concerns about public accommodations are not limited to issues of mobility. Several respondents expressed a need for better accommodation of individuals with hearing impairments or other non-visible disabilities. "I feel that police firefighters and ambulance drivers should have some kind of sign language skills," wrote the parent of a hearing-impaired nine-year-old. Another respondent remarked that "all [hospitals] should have at [least] one person that knows sign to talk to people that sign." Similarly, a 53-year-old woman with mobility and neurological disabilities wrote, "Need more accommodations for upper limb & non-visible — i.e., epilepsy poor sight, etc. disabilities." She did not specify what particular services would be most helpful, however.

Meanwhile, some respondents were critical of the ADA itself. A 42-year-old man with several disabilities (hearing, mobility, neurological, psychological, speech, learning and chronic illness) wrote,

> The Disabilities Act does not do much to protect or help people with brain injuries. The Act has gone overboard with parking places, cost to businesses (that don't need the accessibility) in the millions of dollars, lawyers having a gold mine of lawsuits against businesses before ever warning them that they are not in compliance, playgrounds designed so much for disabled kids who never use them, that they are boring for other kids, too much school resources going to disabled kids, etc.

One respondent, a 56-year-old woman with a mobility impairment and chronic illness, expressed her concern that the ADA may have created a backlash against individuals with disabilities:

> Although the ADA brought curb cuts, it brought problems too. Now if you complain that something is inaccessible, all you get is, 'It's ADA compliant.' I think the laws have made some people more resentful of the disabled and handicapped instead of more compassionate.

A 24-year-old Rogers County woman with multiple disabilities expressed her opinion succinctly: "Lawmakers need to spend a week taking care of a person with disabilities before they make any more laws."

Table 30
Responses:
Accessible homes and apartments are available in your community

	Rural	Suburban	Urban	Oklahoma City County	Tulsa County	All Other Counties	Total
% 1 (Not important)	9.2	7.4	7.4	7.8	6.8	7.8	7.9
% 2	1.6	3.1	1.8	3.1	1.7	2.1	2.3
% 3	10.2	14.5	8.5	9.9	14.5	10.6	11.0
% 4	17.8	19.0	18.7	20.3	21.4	18.6	18.3
% 5 (Very important)	61.1	56.0	63.6	58.9	55.6	60.9	60.5
Mean	4.2	4.1	4.3	4.2	4.2	4.2	4.2
n	314	352	283	192	117	435	103
% 1 (Not satisfied)	27.5	18.7	24.6	25.7	18.0	26.0	22.9
% 2	16.4	19.9	17.9	22.8	21.0	15.4	18.5
% 3	33.1	37.0	31.3	33.3	33.0	34.1	34.5
% 4	12.5	16.5	15.5	12.3	16.0	15.2	14.7
% 5 (Very satisfied)	10.5	7.9	10.7	5.8	12.0	9.3	9.4
Mean	2.6	2.8	2.7	2.5	2.8	2.7	2.7
n	287	316	252	171	100	396	937

Respondents' concerns about the accessibility of public places are paralleled in their concerns about the accessibility of *private* places. Specifically, many feel that accessible homes and aparments are not readily available. (See Table 30.) While relatively few respondents wrote comments on this topic, those who did were united in the opinion that much of the currently available housing is inadequate. A 30-year-old woman with a multiple disabilities (mobility, neurological, chronic illness and other) stated, "I live in Moore, Ok. and finding houses/apartments that have w/c/ [wheelchair] access is close to impossible." Likewise, a 58-year-old woman with a neurological disability wrote,

> Besides the lack of adequate housing available, cost is another major concern for people living with disabilities. Accessible housing needs to mean more than just no steps and wide doors. Kitchens with lowered cabinets, accessible cooking equipment, sinks that can [accommodate] wheelchairs, baths with raised stools, roll in showers, adequate grab bars. Throughout the housing lower type door handles, elevated electrical outlets, push/pull or lower water turn on/off capability, etc. Adequate housing also needs to be made available that are both near to medical facilities along with assorted shopping needs.

A few respondents did note the desirability of easy access to hospitals and retail stores. Location is also important for other reasons, however. As one respondent stated, many of the accessible apartments tend to be located in "low income & bad areas!"

Table 31
Responses:
A central information and referral service is available for disabled persons and their families

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	3.1	3.4	3.0	2.1	0.7	2.5	0.5	1.1	2.1	3.9	2.9
% 2	1.0	2.5	1.2	1.0	1.4	1.5	1.0	1.1	1.5	0.7	1.4
% 3	8.3	10.2	10.8	13.4	7.7	8.3	8.6	4.8	10.8	9.2	9.6
% 4	18.2	21.6	18.0	21.6	16.2	19.1	16.8	21.0	23.1	13.1	20.4
% 5 (Very important)	69.3	62.3	67.1	62.0	73.9	68.6	73.1	72.0	62.6	73.2	65.7
Mean	4.5	4.4	4.4	4.4	4.6	4.5	4.6	4.6	4.4	4.5	4.4
n	192	236	334	292	142	204	197	186	195	153	1067
% 1 (Not satisfied)	23.9	22.4	21.7	23.1	24.0	25.1	29.7	24.6	19.3	21.6	20.0
% 2	21.7	17.1	21.3	24.9	25.6	20.4	18.9	22.9	22.2	18.7	20.1
% 3	31.1	40.5	35.7	34.4	34.1	37.2	31.4	36.6	39.8	36.0	38.0
% 4	14.4	9.5	13.1	11.0	7.8	8.9	8.6	9.7	11.4	11.5	11.5
% 5 (Very satisfied)	8.9	10.5	8.3	6.6	8.5	8.4	11.4	6.3	7.4	12.2	10.3
Mean	2.6	2.7	2.6	2.5	2.5	2.5	2.5	2.5	2.7	2.7	2.7
n	180	210	314	273	129	191	185	175	176	139	973

Table 31 shows the importance of information and referral services. While this need is generally regarded as only moderately important, most respondents report that they are dissatisfied with the information services that are currently available. Moreover, improvements in information and referral are likely to be relatively cost-effective in comparison with many of the other needs identified here. In their written comments, several respondents expressed a need for better dissemination of information. For example, the parent of a 17-year-old boy with neurological, psychological and learning disabilities requested "more publicity on where to get info./help, esp. for older children & young adults." Similarly, a 34-year-old Oklahoma County woman with a learning disability wrote, "it is hard to obtain needed information and services available for handicapped (disabled) adults." The frustrations expressed by a 51-year-old woman with multiple impairments are typical of many individuals with disabilities:

> If a person is in need — it's almost impossible for them to find out where they can go or [whom] to call, the information is not out there. It might be on the [Internet] — I don't own a computer, or live close to someone who does.

"There are resources, but you only hear about them later, after you've gone through so many departments," wrote another respondent.

The need for more complete, reliable and timely information is especially pressing in the more rural parts of the state. The parent of a 12-year-old Texas County girl with several disabilities wrote,

> We live in the Panhandle of Oklahoma and no one around here falls at our feet for any kind

> of assistance. The information that we find out in this area has to come from other parents, that is why I take classes in OKC and go to conferences in OKC so that I can find out more information to bring back to this area for other parents or caregivers.

Similarly, a 56-year-old woman living in a rural area of Pittsburg County wrote, "A lot of agencies that might be available I'm not aware of...I can't get assistance or don't know how to go about it."

Several respondents expressed the belief that inadequate or incorrect information keeps them from getting all the support they are entitled to. For example, the parent of a 11-year-old boy with psychological and learning disabilities stated, "Most of [my needs] are not satisfied, because we are not aware of some of this help." The parent of an 18-year-old woman with visual and neurological disabilities wrote,

> Since our daughter was disabled in 2000, we could have used [an advocate] to show & lead us to help (financial, mental, physical, educational, etc). We feel we have had to look for help which has been hard. And we may still not be getting the help we are [entitled] to.

Similarly, a 77-year-old woman with a hearing impairment wrote, "I did not fill out this (unclear) because I do not get any help. My income is from S.S. Retirement. I've been told others [get] help... I do not know who or how they get it."

Schools and service providers (including physicians and social service workers) were sometimes singled out for their inability or unwillingness to provide important information. For instance, the parent of an 8-year-old Osage County boy with multiple disabilities wrote,

> The DHS in this area knows or helps very little with a child with a disability. They do not know where to send you for help in getting your child's needs met. They do not have information on how to attain services. My son has been disabled since birth however we did not get tested until the age of 5 to know what treatment to do. .... I feel they have done a great injustice to us [in] that if we could have started earlier with services my son's chances would be greatly improved.

Similarly, a 63-year-old woman with visual and mobility impairments wrote, "Doctors and parents do not seem to be aware of what's available for their special needs child." Other respondents described how they learned about available services only when their financial situations became untenable. Some found that they were eligible for assistance months or even years earlier. A 41-year-old man with a mobility impairment wrote,

> I didn't know about programs to help with ph. bills or electric bills for disabled. Until my electricity was about to be d/connected [sic] only then did someone say hey because of your disability you qualify for this; if I would have know about [these] programs I paid like normal people for 10 yrs the program had been around since mid 80's so I unnecessarily paid because it's not made known upfront. People [deceive] or hide programs unless it's absolutely necessarily. How do we know about these things unless someone else handicapped tells you[?]

Several respondents voiced the need for a central source of information that would provide referrals for necessary services and support. While that is one mission of the Oklahoma Office of Handicapped Concerns (OHC), it appears that many respondents seemed unaware of this. For example, a 21-year-old woman with cerebral palsy who lived in a suburban part of Pittsburg County wrote,

> I wish there was a place to go for people with [disabilities] to get help on their driver's licenses, or a place that would help w/ jobs, housing and necessary needs.

Similarly, a 39-year-old Cleveland County woman with a mobility impairment and chronic illness wrote,

> For an individual who has recently become disabled from an illness, where do you start to find out info on programs to help with finances housing [expenses]? There is not enough info [visibly] to know where to start. We lost our home & job and are not [receiving] help from SS/or workers Comp and may soon [lose] our Med Ins.

The parent of a 10-year-old girl with several disabilities suggested that the state distribute a free information guidebook for individuals with disabilities:

> We should not have to pay for a source book for resources — we should be given something perhaps by our pediatricians to guide us. There is a great lack of knowledge.

Legal Support and Advocacy

Table 32
Responses:
Training is available to teach disabled people and parents of disabled children how to advocate for their rights

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	2.2	4.5	1.3	2.2	0.0	3.1	1.6	0.6	1.7	2.1	2.4
% 2	0.0	0.9	0.3	1.1	1.5	0.0	0.0	0.0	1.7	0.0	1.0
% 3	5.0	6.7	6.0	6.6	3.8	3.1	1.6	1.7	7.8	5.5	6.0
% 4	9.4	14.3	12.7	12.8	9.2	14.3	13.2	16.0	13.4	9.6	13.2
% 5 (Very important)	83.3	73.5	79.7	77.3	85.5	79.6	83.7	81.7	75.4	82.9	77.5
Mean	4.7	4.5	4.7	4.6	4.8	4.7	4.8	4.8	4.6	4.7	4.6
n	180	223	300	273	131	196	190	175	179	146	1008
% 1 (Not satisfied)	37.0	33.8	37.7	43.0	43.9	38.5	44.6	38.0	36.6	33.9	36.0
% 2	23.6	22.4	17.6	16.8	18.7	22.3	17.7	21.5	18.9	12.6	19.5
% 3	21.8	24.4	29.3	28.1	22.0	24.6	20.6	24.5	29.9	36.2	27.9
% 4	8.5	9.5	8.1	7.8	8.1	5.6	8.0	6.1	8.5	10.2	9.4
% 5 (Very satisfied)	9.1	10.0	7.3	4.3	7.3	8.9	9.1	9.8	6.1	7.1	7.1
Mean	2.3	2.4	2.3	2.1	2.2	2.2	2.2	2.3	2.3	2.4	2.3
n	165	201	273	256	123	179	175	163	164	127	902

Table 33
Responses:
Affordable legal help is available to disabled persons
who file Social Security appeals, discrimination cases, etc.

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.7	4.0	2.0	2.2	3.7	2.6	3.8	1.2	1.1	0.7	2.2
% 2	0.6	0.4	0.7	1.1	0.0	0.5	0.0	0.6	1.1	0.0	0.8
% 3	1.1	6.3	3.3	6.9	2.2	4.6	2.2	4.0	5.4	2.8	5.2
% 4	10.6	14.3	10.6	10.2	7.5	11.2	9.1	12.7	11.4	9.1	12.3
% 5 (Very important)	86.1	74.9	83.4	79.6	86.6	81.1	84.9	81.5	81.0	87.4	79.5
Mean	4.8	4.6	4.7	4.6	4.7	4.7	4.7	4.7	4.7	4.8	4.7
n	180	223	302	274	134	196	186	173	184	143	1006
% 1 (Not satisfied)	37.0	32.7	36.0	37.1	44.4	33.9	35.8	28.9	46.2	40.2	33.7
% 2	21.8	17.9	20.1	17.0	21.0	25.0	21.4	28.3	11.6	12.9	19.4
% 3	27.3	31.6	31.3	33.6	24.2	29.4	29.5	30.2	26.6	27.3	31.2
% 4	7.3	7.7	5.8	5.8	1.6	5.6	3.5	6.3	10.4	12.1	8.3
% 5 (Very satisfied)	6.7	10.2	6.8	6.6	8.9	6.1	9.8	6.3	5.2	7.6	7.5
Mean	2.2	2.4	2.3	2.3	2.1	2.3	2.3	2.3	2.2	2.3	2.4
n	165	196	278	259	124	180	173	159	173	132	235

Many individuals with disabilities do not have a clear understanding of their legal rights. It is therefore not surprising that the vast majority of ODS respondents consider advocacy training "very important" (Table 32). Individuals with developmental, learning, and/or psychological disabilities are especially likely to recognize the need for this kind of training. As Table 33 shows, an even larger proportion of respondents are in need of affordable legal assistance. Nearly 80% characterize this need as "very important," and less than 16% are satisfied with the current state of affairs.

In their written comments, quite a few respondents mentioned the inadequacy of public legal support in the state of Oklahoma. A 46-year-old woman with multiple disabilities (visual, hearing, neurological, psychological, and chronic illness) distilled the views of many respondents when she wrote:

> The level of [advocacy] in this state is extremely poor, especially any place outside of OK city. There aren't any places to find out about your "rights" as a disabled person [I have found out about my rights on the internet].

A 54-year-old woman with a chronic illness wrote, "There needs to be more offices such as legal aid to represent people." Similarly, the parent of a 21-year-old man with multiple disabilities wrote, "We had many problems getting help for our son. No one seemed to care what was done or what was needed to be done."

Many respondents simply do not know where to turn for legal advice. A 46-year-old woman with a neurological disability described her situation:

> I have not been able to find any legal assistance regarding discontinuance of my disability

> [benefits] & extended family members have & are providing financial assistance. This assistance is becoming burdensome for my family & I am afraid of what my future holds! If anyone can tell me who can provide legal assistance, please call me.

A 34-year-old female respondent who felt she was a victim of hiring discrimination likewise did not know where to find assistance:

> I was wondering if [there's] a way I can sue her [the employer who would not hire me], cause I don't see that [as] right, that she turns me down, cause of my [disability]. [It's] not right[.] So could somebody help [me] get a lawyer... [?] ... Everybody agrees with me I should sue this woman.

Another respondent, a 46-year-old female with a variety of disabilities (visual, hearing, neurological, psychological, and chronic illness), argued that a single state office should provide legal support for individuals with disabilities:

> There needs to be a 'Department for the Disabled' so that we could have a source to go to, to find out about our "rights." To find an advocate when we truly need one, which is usually a very STRESSSFUL time, & our health problems will usually get worse also. Another good reason for a "Dept. for the Disabled" is to [separate] the DISABLED from Welfare. With all the Welfare to Work cuts, the Disabled & Elderly got cut too! No allowance to [separate] us in programs such as Housing, Food Stamps etc. I got my food stamps cut from $52 to $10. Then when my rent was increased $85 my food stamps went up to $22 (a $12 increase vs. the $85 lost in rent cost).

Many respondents chronicled their struggles to obtain legal advocacy, and several noted that it was difficult if not impossible to obtain adequate legal representation in appeals cases involving state or federal benefits. (The vast majority of respondents cannot afford to hire private lawyers.) For instance, the parent of a 1-year-old girl with an unspecified disability wrote,

> Amy [daughter] was turned down by SS...and we don't have any lawyer to advise us. So now we have to [reapply] and see if they refuse her again.

Similarly, a 54-year-old woman with a neurological disability and chronic illness wrote,

> I have been [treated] awful trying to get my SSI — My lawyer was fired from the judge [because] my lawyer did not come to court because his wife was having a baby. Now I cannot get a lawyer to take my case. I have to [appear] in court myself with my husband, who is on SSI already. We don't have the education, we know we will be [slaughtered], But, we don't have a choice. But if I am turned down again, I will fight it and again, and again — Because I am being [discriminated] against, Because I don't have insurance or [a lot] of money.

Several respondents who had sought legal representation from the state expressed dissatisfaction with the quality of services provided. For example, a 42-year-old woman with multiple disabilities (mobility, neurological, and chronic illness) expressed her suspicion that many bureaucratic requirements are intended to discourage individuals with disabilities from obtaining legal assistance: "I still have no attorney for EEOC claim from March 2001 — Time is [meant] to discourage me and I have to work to meet my responsibility." Similarly, a 46-year-old female with a variety of disabilities (visual, hearing, neurological, psychological, chronic illness and 'other') wrote,

> I have been fighting for my rights for a year. It is ruining my health, besides the constant STRESS. I have numerous disabilities & called & called every possible lead for some ADVOCATE to help. I finally got a lawyer from legal aid, to stay where I am...My legal aid lawyer told me 'Just because you have Disability Rights doesn't mean you are going to get them' and she was the best advocate I could get. I kept telling her how ill I was with my Crohn's and she didn't believe me either.

Many respondents also feel that individuals with disabilities can suffer negative repercussions (political, economic and social) if they try to assert their rights. For example, a 59-year-old woman with a psychological disability wrote,

> My heart goes out to those who due to their illnesses are afraid to speak up for fear of being called trouble makers. I speak with experience for when I would inform my peers as to their rights I received warning that I was "rocking the boat" as a result I left my advocacy job, the center I attended and when I did my Social Security [Supplemental Insurance] was lost but at least I am free to speak.

Similarly, a 65-year-old man with a mobility impairment stated,

> I believe [the] Governor's Committee should provide a private lawyer to fight for people with disabilities who file a grievance with O.C.R. [Office of Civil Rights] in Dallas because O.C.R. to me is a big joke. We have federal laws that [say] 1 thing while our O.C.R. investigator [does another] thing: when we file a complaint our offices such as O.C.R./Attorney General/Governor/and a big amount of legislator have a reason to turn against those classed as whistle blowers such as myself.

Several respondents also complained that public legal assistance agencies are especially unresponsive to their needs. Two parents of children with disabilities, one in Tulsa County and another in Oklahoma County, reported that public legal services agencies would not return their phone calls.

Sensitivity Training

Many ODS respondents described a widespread lack of sensitivity toward individuals with disabilities and 28 respondents (6.2% of those who provided written comments) made mention of this concern in their written feedback. Especially troubling is the insensitivity shown by teachers, police, and medical personnel. A 48-year-old woman with a hearing impairment summarized the sentiments of several respondents when she wrote,

> Oklahomans certainly need a huge sensitivity training concerning their attitudes toward disabled people. They are rude beyond belief.

Several respondents complained that people often stereotype and/or have preconceived misconceptions about individuals with disabilities. For example, the parent of an 8-year-old girl with visual and mobility impairments wrote,

> Community Issues: General ignorance of the handicapped populations abilities in general. ex. can't walk can't think. Blind = Ignorant. example — DHS case worker asked if my 3 yr. old daughter was retarded with my child sitting in my lap. My daughter looked around at me and rolled her eyes at me then later asked why that lady said that.

Similarly, another respondent who filled out the questionnaire on behalf of an 11-year-old boy with hearing and speech impairments wrote,

> We need to educate people and children about different disabilities better. It is sad when children and adults see a child with hearing aids, they think they are stupid because they do not talk the same as normal kids. We need to offer sign classes as a foreign language, all sign language not just ASL [American Sign Language].

A 22-year-old woman with a learning disability complained, "There is a lack of universal understanding for those with disabilities. [Too] bad we can't sit them all down @ one time & explain everything to them."

Some respondents described the social isolation that often results from disability. For example, a 65-year-old woman with a chronic illness wrote,

> Most people want to help — But you become forgotten sometimes — I often feel I am in solitary confinement when I have to stay home for long lengths of time. Part of this is caused by living in the country — or because I'm a mean ole woman!

Meanwhile, the mother of a 12-year-old boy Cherokee County boy with a variety of disabilities (visual, neurological, psychological, speech, learning and mental retardation) described how she and her son had been mistreated at a local pharmacy:

> When I presented my son's Medicaid card at our local pharmacy, we were referred to as "one of those welfare sponges", even though I work 40+ hours a week as a healthcare professional [nurse]. (We changed our pharmacy that day.)

Similarly, a 49-year-old woman with a psychological disability described how others were unwilling to help her because of what she perceived to be the stigma associated with disability and welfare receipt:

> Our 87 Chevy Astro van was broke down in the City of Konawa for 30 days and [no one would] help me (nor my husband) because I was mentally disabled and we was poor and drawing SSI and [Medicaid].

Table 34
Responses:
Police and other individuals are sensitive to the needs of disabled persons

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	0.5	2.7	0.3	0.4	1.5	1.0	1.1	0.0	1.6	1.4	1.3
% 2	0.5	0.0	0.3	1.1	0.0	0.0	0.5	0.6	0.0	0.7	0.5
% 3	1.6	4.0	3.5	6.1	2.3	3.5	4.2	2.2	4.8	4.1	4.1
% 4	10.4	11.5	9.3	12.1	10.6	12.6	9.5	15.7	12.3	3.4	11.9
% 5 (Very important)	86.9	81.9	86.5	80.4	85.6	82.8	84.7	81.5	81.3	90.3	82.2
Mean	4.8	4.7	4.8	4.7	4.8	4.8	4.8	4.8	4.7	4.8	4.7
n	183	226	312	280	132	198	189	178	187	145	1017
% 1 (Not satisfied)	20.8	25.1	23.9	22.2	34.1	24.7	26.6	17.8	25.4	30.8	22.5
% 2	19.0	20.1	14.3	15.4	18.3	24.7	16.8	18.4	16.2	11.5	16.6
% 3	34.5	26.6	35.2	37.2	23.0	26.9	32.9	37.4	37.0	32.3	33.2
% 4	13.7	14.6	14.7	15.8	13.5	15.9	12.7	17.8	13.3	15.4	16.2
% 5 (Very satisfied)	11.9	13.6	11.9	9.4	11.1	7.7	11.0	8.6	8.1	10.0	11.5
Mean	2.8	2.7	2.8	2.7	2.5	2.6	2.6	2.8	2.6	2.6	2.8
n	168	199	293	266	126	182	173	163	173	130	924

Table 34 may help reveal the extent of the problem. Eight-two percent of respondents feel that sensitivity to individuals with disabilities is "very important" while less than 12% are "very satisfied" with the current situation. Individuals with psychological disabilities are especially likely to report that police and other officials are insensitive to their needs and conditions. Several respondents — in particular, men with developmental or psychological problems — asserted that police officers routinely mistreat individuals with disabilities. Next to this question ("Police and other individuals are sensitive..."), a 40-year-old man with psychological and learning disabilities wrote, "No way." A 27-year-old man with mental retardation wrote, "No No No." Likewise, a 35-year-old Creek County man with a speech impairment wrote, "they [police and other officials] [harass] me." The president of an organization that provides services to individuals with disabilities described how one of her clients had been mistreated by a police officer:

> I personally had an aphasic pt. who was arrested at a rock concert because he couldn't speak. He bumped into a woman who was holding an alcoholic beverage- the beverage spilled. She was actually an off-duty policy officer who had him arrested for public intoxication & resisting arrest because he couldn't state his name or address. He was unable to phone his wife because of the aphasia. Only after two days, his wife discovered he'd been arrested. During his incarceration, he was beaten and had his watch stolen. It wasn't even a case of 'his story against theirs.' Is this sensitivity by law enforcement agencies to individuals with disabilities?

Table 35
Responses:
The media portray disabled people in a positive light

	Visual imp.	Hearing imp.	Mobility imp.	Neuro. dis.	Psych. dis.	Speech imp.	Learning dis.	Mental ret.	Chronic illness	Other	Total
% 1 (Not important)	1.1	3.1	1.3	0.7	1.5	2.0	2.1	0.6	1.6	0.7	1.7
% 2	1.1	0.0	0.0	1.1	0.0	0.0	0.0	0.0	0.0	0.7	0.6
% 3	3.8	9.3	7.4	8.6	5.2	8.5	6.3	7.3	8.6	7.4	8.0
% 4	12.4	15.9	12.6	12.6	12.7	15.1	13.2	14.6	11.8	12.1	13.4
% 5 (Very important)	81.6	71.7	78.7	77.0	80.6	74.4	78.4	77.5	78.1	79.2	76.3
Mean	4.7	4.5	4.7	4.6	4.7	4.6	4.7	4.7	4.6	4.7	4.6
n	185	226	310	278	134	199	190	178	187	149	1020
% 1 (Not satisfied)	20.5	23.8	20.2	23.5	28.1	20.5	25.3	15.9	28.6	25.0	20.8
% 2	24.0	22.8	24.7	21.3	26.6	23.2	20.1	22.4	20.6	23.5	21.6
% 3	36.8	31.6	34.6	37.3	25.8	38.9	37.4	40.6	32.0	38.2	36.3
% 4	11.7	12.1	14.7	12.7	11.7	13.5	12.6	15.3	15.4	7.4	14.2
% 5 (Very satisfied)	7.0	9.7	5.8	5.2	7.8	3.8	4.6	5.9	3.4	5.9	7.1
Mean	2.6	2.6	2.6	2.5	2.4	2.6	2.5	2.7	2.4	2.5	2.7
n	171	206	292	268	128	185	174	170	175	136	943

Insensitivity may be linked to misinformation — specifically, to television programs and other media which portray individuals with disabilities in a negative light. Table 35 summarizes the extent of this problem. Perhaps not surprisingly, individuals with psychological disabilities are especially critical of the media. The parent of a 38-year-old (disability not specified) expressed the view of many respondents: "There is nothing positive about the media. Everything is negative or portrayed that way." Similarly, a 38-year-old man with a psychological disability wrote:

> Any time the media mentions psychologically disabled persons, it is usually in a disparaging way or in connection with an act of violence. This perpetuates stigma; which encourages such disabled ones to stay "in the closet."

On the other hand, the parent of a 7-year-old boy with multiple disabilities (mobility, neurological, and learning) recognized the media's right to dramatize — to present a view of the world that is not necessarily realistic. "[The media] can't be controlled without censorship," the respondent stated.

A number of respondents expressed a need for better education and sensitivity training to raise peoples' awareness. A 25-year-old man with a hearing impairment wrote, "it will be good if some courses about dealing with disabled persons are offered for all people in universities, hospitals, police departments, etc." Similarly, a 45-year-old respondent with mobility and neurological impairments complained about the current state of research and education regarding disability in America:

> Professional research and publications are sorely lacking. Even for those in the disabled-American community with the training, opportunities are rare and if available too clinically sterile for the gen. public to understand the [dilemmas] and [dichotomies] of being disabled in a society that values the 'fleeting' human attributes.

A 46-year-old respondent with a visual impairment (legal blindness) provided suggestions for the kind of educational training that might be provided:

> The non-handicapped in workplaces need to be educated on how to communicate + move around with fellow workers that are disabled. [In] my case legally blind. Chairs are left out from tables, etc. When they walk around they don't think about the blind person walking too, cutting in front of them, going around corners like [they are] the only ones there or that [everyone] can see as well as they can.

For a few respondents, sensitivity involved careful attention to language when speaking about individuals with disabilities. For example, two respondents favored the consistent use of "people first" language. Two respondents felt that the Office of Handicapped Concerns [OHC] should consider changing its name.

Unrecognized and "Hidden" Disabilities

In their written comments 23 respondents voiced concerns that individuals with certain kinds of disabilities are especially unlikely to get the support and services they need. In particular, respondents with "hidden disabilities" are often overlooked by both government agencies and the general public. For example, a 51-year-old man with a psychological disability wrote,

> There is a line between being 'disabled' and being 'normal.' There is [a] significant difference in the way people see physical disabilities and mental disabilities. There is a tendency for a disabled person to 'act' more disabled because that is the only way that we are acknowledged as needing special considerations or [accommodations]. I refuse to give in to this and continue to keep quiet about being bi-polar. It simply does not afford any advantage to admit a disability.

Likewise, a 46-year-old woman with a mobility impairment and a chronic illness wrote,

> I've lived with Rheumatoid Arthritis since childhood...It's a very painful, crippling disease with unexpected complications as the years go by. My point is, in many situations I look normal & healthy but would appreciate the benefits of those who are visibly disabled.

A 42-year-old woman with multiple disabilities (mobility, neurological, chronic illness and other) expressed a similar sentiment:

> If you don't appear physically ill you must be faking or [sponging] off [the] system. I have numerous well documented chronic disorders and [cannot receive] my [benefits], legal representation, protections of rights, etc.

A 51-year-old man with a chronic illness further remarked,

> Some [people with disabilities] have problems getting assistance because they do not look handicapped such as heart patients, people with liver and kidney problems. Because of their physical appearances their needs are not being provided.

Respondents with other disabilities such as hearing impairments, autism and multiple chemical sensitivity also maintained that that their needs are often unrecognized due to the absence of obvious signs of disability. As the close relative of an 18-year-old man with hearing and psychological disabilities stated, "[he] looks 'normal', so people don't always understand." Similarly, a 56-year-old woman with a mobility impairment and chronic illness remarked that individuals with chronic illness are often overlooked:

> Society still does not understand "chronic illness." You're either supposed to get well or die...I prefer to consider myself handicapped rather than disabled because I am able to do most things on good days, albeit with difficulty. But when people see me doing something on one day, they do not understand when I cannot do it on other days and sometimes refuse the help I need...Many people in the US are not chronically ill and do not understand how physically, emotionally and financially devastating it can be.

Some respondents also described how a lack of awareness can contribute to embarrassment and discomfort. A 43-year-old woman with hearing and speech impairments wrote,

> Because I have what I consider a hidden disability (hearing & speech impairment) sales clerks, police tend to become frustrated or laugh & irritable when I don't understand or answer inappropriately and my children become quite upset/[embarrassed]. Need support system/[counseling] for children & teens of disabled parents. My children find me to be very [embarrassing] & ask me not to speak at their schools, to their teachers or out in public & especially don't sign!

A 33-year-old man with a learning disability noted the high social and economic costs of this lack of awareness:

> At the OU health sciences center neuro-psyche Dept...I was diagnosed as non-verbal learning disability (similar to Asperger's) in 1999. Currently there are no programs to [aid] these people in Oklahoma and no way to get disability money. This is a subtle form of disability. On the surface, nothing is wrong except oddness and clumsiness. But their success rate is virtually nil because of their poor social skills. If only [there] could be a program at least to teach them social skills, but also perhaps to work with employers so they could understand their lack of social skills.

Several respondents complained that the general population associates disability with being in a wheelchair. For example, a 53-year-old woman with mobility and neurological disabilities wrote, "Anything but a wheelchair & nobody thinks [you're] disabled. Need more accommodations for upper limb & non-visible — i.e., epilepsy poor sight, etc. disabilities." Similarly, an 18-year-old woman with a psychological disability wrote,

> I don't think that enough attention is getting paid for the deaf & blind. People don't realize that they are [handicapped] as well. Most people when they hear the word '[handicapped]' they think 'wheelchair.' Or a mentally disabled person. Deaf & blind people are not getting enough help in the smaller Oklahoma cities.

Several respondents also complained about inadequate attention to the needs of those with traumatic brain and head injuries. For example, a 42-year-old man with a variety of disabilities (hearing, mobility, neurological, psychological, speech, learning and chronic illness) wrote, "The Disabilities Act does not do much to protect or help people with brain injuries." The parent of a 40-year-old adult with neurological and psychological disabilities complained that that there were insufficient job opportunities for those with head injuries. Likewise, the parent of a 30-year-old woman with multiple disabilities wrote, "There is nothing that I'm aware of in Okla. for severely brain injured [adults]. TBI of Okla. does not address her level [seriously injured]."

Other Comments

While basic needs are obviously of central importance, there is considerable sentiment among the ODS respondents that quality-of-life issues should also be addressed. For instance, a 31-year-old man with a chronic illness stated, "not enough emphasis placed on emotional and spiritual health... [No appropriate services] have ever been offered." Likewise, several respondents mentioned the lack of recreational opportunities for individuals with disabilities. A 65-year-old woman with chronic obstructive pulmonary disease (COPD) wrote, "Many programs (community) [offered] to the older person are aimed at the healthy senior citizen," and a 54-year-old woman with a hearing impairment stated, "activity centers for people under 55 years are very few."

Two respondents asserted that the system of disability benefits discourages individuals with disabilities from getting married.[25] For example, the parent of a 21-year-old man with a variety of disabilities (neurological, psychological, speech and mental retardation) wrote, "With the existing laws today, if people with disabilities want to get married, they lose their funding. Therefore, many couples end up 'co-habitating' instead of getting married." Similarly, the parent of a child with a disability wrote:

> Individuals with disabilities due to Medicaid/Medicare guidelines are financially forced to "live together." If they marry coverage for prescriptions cut or taken away all together. Shouldn't we encourage marriage?

---

[25] Marriage can affect the receipt of federal disability benefits in several ways. If an individual is receiving disability benefits on his or her own record, his or her payments will continue and he or she need not report the marriage. However, an individual disabled before age 22 who receives benefits on the Social Security record of a parent or grandparent will generally no longer receive benefits after marriage (unless he or she marries a person receiving certain types of Social Security benefits). The benefits paid to a child of someone who qualifies for disability benefits will always end if the child marries (U.S. Social Security Administration 2002).

Quite a few respondents stressed that nonmetropolitan residents are often worse off than those living near Oklahoma City or Tulsa. For instance, the parent of a 12-year-old girl with multiple disabilities (mobility, neurological, speech, chronic illness and mental retardation) complained that appropriate support groups are unavailable in rural areas. Likewise, a 26-year-old Comanche County woman with a neurological impairment wrote, "In SW Ok [we] have such a long way to go...compared to other areas in the state." A 51-year-old Creek County man felt similarly:

> I live in an area that is called a grey zone. I live [too] far to get any help from any organization who could help me. I live 40 minutes from Tulsa. No one there wants to help me. I've tried to get help in OK City. That was another horror story in [itself].

Finally, a 47-year-old Kay County man enumerated the challenges of living with a chronic illness in North-Central Oklahoma:

> The world has become a very 'undetached' place to be when a person is living with '1' disability — not to mention '3'! What's up with the Northern part of Central Oklahoma's reasoning on —
>
> 1. No adequate doctors in this area (that are willing to doctor) (+H.I.V. + Hep C) patients;
>
> 2. No medical doctors or equipments or meds in large Northern Hospitals that refuse or say they "can't help or doctor"' because of lack of qualified doctors <u>and</u> or Hosp. (must go to either Tulsa or OKC — What about Ponca City? There are many infected chronic illness patients here! It's not fair;
>
> 3. Why should I and others be made to feel like early day '[lepers]'?

Summary and Conclusions

Like all Oklahomans, individuals with disabilities need food, clothing, shelter, health care, education, employment, transportation, and a means of achieving dignity and respect. Unfortunately, these needs remain unmet for a significant proportion of individuals with disabilities.

Drawing on both the questionnaire results and the written comments volunteered by respondents to the 2001-2002 Oklahoma Disability Survey (ODS), this report has chronicled the concerns of individuals with disabilities in the state of Oklahoma. Some of the more pressing needs mentioned by respondents include

- financial assistance to pay for food and shelter
- elimination of unnecessary bureaucracy in the process of applying for and receiving government benefits and services
- health insurance coverage
- skilled and caring health care providers, including personal care attendants

- affordable medical supplies and prescription drugs
- respite care for parents and families of individuals with chronic disabilities
- humane treatment at long-term residential care facilities
- in-home services for individuals with serious disabilities who wish to live independently
- trained teachers and administrators who are sensitive to the needs of children with disabilities
- compliance with individualized educational programs (IEPs) in the schools
- career training and employment opportunities for individuals with disabilities
- transportation to work and to social activities
- accessibility in apartments and public places for individuals with a wide range of disabilities
- advocacy and legal support
- greater sensitivity to the needs of individuals with disabilities (especially among police, teachers, health care workers, and administrative personnel)
- clear, consistent, and timely information about the services available to individuals with disabilities
- the establishment and maintenance of services and support in outlying and rural parts of the state.

While some of these needs can be met with only a modest commitment of resources, others will take some time and require a greater level of commitment on the part of the state and the general public. For example, while it is relatively simple and inexpensive to distribute information about the kinds of services available to individuals with disabilities, considerable time and effort — and certainly a greater expenditure — will be needed to ensure humane treatment at residential living facilities throughout the state.

The 2001-2002 ODS asked respondents to rate the importance of various needs, and to indicate their satisfaction that each need is currently being met. Tables 36 and 37 present the rankings of the 56 items included in the questionnaire. As shown in Table 36, respondents feel that health care is the single most pressing issue. Specifically, they are concerned about public insurance coverage for routine medical care, emergency medical procedures, and prescription drugs. Quite a few respondents feel that their health is being jeopardized by Medicaid's restriction on prescription drugs (no more than three prescriptions per month). The tables further reveal that financial needs are very important, along with educational and employment/vocational needs.

Table 36
Ranking of Needs from Most Important to Least Important Based on Mean Scores

Rank	Mean	
(1)	4.7793	Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for routine medical care (doctor visits, etc.).
(2)	4.7693	Insurance companies do not discriminate on the basis of disability.
(3)	4.7689	Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for emergency medical procedures and surgery.
(4)	4.7570	Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for prescription drugs.
(5)	4.7498	Affordable prescription drugs are available to individuals with disabilities.
(6)	4.7325	Police and other officials are sensitive to the needs of disabled persons.
(7)	4.7314	Social Security Disability Insurance and Supplemental Security Income (SSI) provide adequate financial help to disabled individuals who cannot work.
(8)	4.7280	Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for medical supplies (wheelchairs, hearing aids, etc.).
(9)	4.7144	School administrators and teachers are sensitive to the needs of disabled students.
(10)	4.7050	Mental health and health care providers are sensitive to the needs of persons with disabilities.
(11)	4.7025	Utility bills are affordable.
(12)	4.6620	Affordable legal help is available to disabled persons who file Social Security appeals, discrimination cases, etc.
(13)	4.6547	Effective academic programs are available for disabled students.
(14)	4.6507	Employers have a positive attitude about hiring people with disabilities.
(15)	4.6494	Adaptive educational materials and needed support services (i.e., speech therapists, translators, etc.) are readily available to disabled students.
(16)	4.6324	The media portray disabled people in realistic ways.
(17)	4.6317	Financial help is available for needed adaptive aids and equipment for individuals with disabilities.
(18)	4.6270	Workplaces provide reasonable accommodations for individuals with disabilities.
(19)	4.6241	Disabled children can get the services and care they need early enough to improve their opportunities in life.
(20)	4.6240	Training is available to teach disabled people and parents of disabled children how to advocate for their rights.
(21)	4.6206	The media portray disabled people in a positive light.
(22)	4.6168	Vocational rehabilitation provides disabled individuals with the training they need to obtain meaningful employment.
(23)	4.6145	State and community agencies provide financial help for disabled persons who cannot work but who need support while appealing Social Security or SSI benefit denials or while waiting for benefits to start.
(24)	4.6144	There is adequate support for independent living for disabled individuals who wish to avoid institutionalization.
(25)	4.6026	Personal aides are sensitive to the needs of individuals with disabilities.
(26)	4.5932	There is strict enforcement of the Americans with Disabilities Act.
(27)	4.5892	A variety of job opportunities are available for disabled persons.
(28)	4.5724	Disabled persons have adequate opportunities to change jobs or advance in their careers.
(29)	4.5694	Handicapped parking ordinances are strictly enforced.
(30)	4.5620	Disabled persons can vote easily at regular polling places.
(31)	4.5551	Buildings, parks, businesses and pedestrian areas are accessible to persons with all kinds of disabilities.
(32)	4.5542	Disabled persons can vote by absentee ballot when necessary.
(33)	4.5467	Assistance in learning new ways to accomplish daily tasks is available to individuals with disabilities.
(34)	4.5415	Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for attendant care.
(35)	4.5408	Good job placement is available from state rehabilitation and employment agencies and from other employment programs.

continued

Table 36 (continued)
Ranking of Needs from Most Important to Least Important Based on Mean Scores

Rank	Mean	
(36)	4.5359	Good quality attendant care is available.
(37)	4.5312	Good career counseling is available for disabled persons.
(38)	4.5217	Employed individuals with disabilities have adequate financial support from state and local agencies.
(39)	4.5172	Financial help is available to make a home or apartment accessible for individuals with disabilities.
(40)	4.5038	Public transportation allows individuals with disabilities to go where they need to go.
(41)	4.5036	Disabled students can participate in the extra-curricular activities offered by their schools.
(42)	4.5019	Nursing care is available to individuals with disabilities.
(43)	4.4906	Housing rental assistance is available for disabled individuals when needed.
(44)	4.4781	Nursing home care is responsive to the needs of individuals with disabilities.
(45)	4.4615	Temporary care (respite and/or attendant care is) available to ease the burden of regular caregivers.
(46)	4.4601	Financial help is available for quality attendant care.
(47)	4.4461	A central information and referral service is available for disabled persons and their families.
(48)	4.4106	Support groups are available to disabled persons and their families.
(49)	4.4083	A variety of social and recreational activities are available for disabled children and adults.
(50)	4.4057	Public transportation (for disabled individuals) operates during convenient hours.
(51)	4.3876	Financial help is available for housekeeping assistance for individuals with disabilities.
(52)	4.3376	Day care programs are available for disabled children.
(53)	4.3301	Financial help is available for chore services (shopping, lawn care, etc.) for individuals with disabilities.
(54)	4.3110	Group homes for mentally and physically disabled children are available in your community.
(55)	4.2123	Accessible homes and apartments are available in your community.
(56)	3.9368	Programs and services designed to service the disabled community are provided by individuals with disabilities.

Table 37
Ranking of Needs from Most Satisfied (Need is Being Met) to Least Satisfied (Need is Not Being Met) Based on Mean Scores

Rank	Mean	
(1)	3.3862	Disabled persons can vote by absentee ballot when necessary.
(2)	3.3424	Nursing home care is responsive to the needs of individuals with disabilities.
(3)	3.0912	Disabled persons can vote easily at regular polling places.
(4)	2.9017	Buildings, parks, businesses and pedestrian areas are accessible to persons with all kinds of disabilities.
(5)	2.8734	Support groups are available to disabled persons and their families.
(6)	2.8045	Programs and services designed to service the disabled community are provided by individuals with disabilities.
(7)	2.7760	Police and other officials are sensitive to the needs of disabled persons.
(8)	2.7459	Nursing care is available to individuals with disabilities.
(9)	2.7283	Public transportation allows individuals with disabilities to go where they need to go.
(10)	2.7184	A central information and referral service is available for disabled persons and their families.
(11)	2.6916	Accessible homes and apartments are available in your community.
(12)	2.6763	Mental health and health care providers are sensitive to the needs of persons with disabilities.
(13)	2.6663	Disabled children can get the services and care they need early enough to improve their opportunities in life.
(14)	2.6608	Handicapped parking ordinances are strictly enforced.
(15)	2.6522	The media portray disabled people in a positive light.
(16)	2.6470	Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for emergency medical procedures and surgery.
(17)	2.6348	Vocational rehabilitation provides disabled individuals with the training they need to obtain meaningful employment.
(18)	2.6288	Public transportation (for disabled individuals) operates during convenient hours.
(19)	2.6259	Assistance in learning new ways to accomplish daily tasks is available to individuals with disabilities.
(20)	2.6156	Personal aides are sensitive to the needs of individuals with disabilities.
(21)	2.6008	Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for routine medical care (doctor visits, etc.).
(22)	2.5934	There is strict enforcement of the Americans with Disabilities Act.
(23)	2.5933	A variety of social and recreational activities are available for disabled children and adults.
(24)	2.5845	Adaptive educational materials and needed support services (i.e., speech therapists, translators, etc.) are readily available to disabled students.
(25)	2.5819	School administrators and teachers are sensitive to the needs of disabled students.
(26)	2.5616	Good quality attendant care is available.
(27)	2.5546	The media portray disabled people in realistic ways.
(28)	2.5290	Workplaces provide reasonable accommodations for individuals with disabilities.
(29)	2.5160	Financial help is available for needed adaptive aids and equipment for individuals with disabilities.
(30)	2.5130	Housing rental assistance is available for disabled individuals when needed.
(31)	2.5110	Effective academic programs are available for disabled students.
(32)	2.4984	Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for medical supplies (wheelchairs, hearing aids, etc.).
(33)	2.4827	Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for prescription drugs.
(34)	2.4809	Good job placement is available from state rehabilitation and employment agencies and from other employment programs.
(35)	2.4791	Day care programs are available for disabled children.

continued

Table 37 (continued)
Ranking of Needs from Most Satisfied (Need is Being Met)
to Least Satisfied (Need is Not Being Met) Based on Mean Scores

Rank	Mean	
(36)	2.4713	Disabled students can participate in the extra-curricular activities offered by their schools.
(37)	2.4558	Financial help is available for quality attendant care.
(38)	2.4510	Financial help is available for housekeeping assistance for individuals with disabilities.
(39)	2.4465	Group homes for mentally and physically disabled children are available in your community.
(40)	2.4452	There is adequate support for independent living for disabled individuals who wish to avoid institutionalization.
(41)	2.4295	Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for attendant care.
(42)	2.4276	Good career counseling is available for disabled persons.
(43)	2.4229	Affordable prescription drugs are available to individuals with disabilities.
(44)	2.4180	Temporary care (respite and/or attendant care is) available to ease the burden of regular caregivers.
(45)	2.4159	Financial help is available to make a home or apartment accessible for individuals with disabilities.
(46)	2.3652	Affordable legal help is available to disabled persons who file Social Security appeals, discrimination cases, etc.
(47)	2.3366	Financial help is available for chore services (shopping, lawn care, etc.) for individuals with disabilities.
(48)	2.3204	Training is available to teach disabled people and parents of disabled children how to advocate for their rights.
(49)	2.2784	Social Security Disability Insurance and Supplemental Security Income (SSI) provide adequate financial help to disabled individuals who cannot work.
(50)	2.2474	Employed individuals with disabilities have adequate financial support from state and local agencies.
(51)	2.2400	Disabled persons have adequate opportunities to change jobs or advance in their careers.
(52)	2.2080	Utility bills are affordable.
(53)	2.1389	A variety of job opportunities are available for disabled persons.
(54)	2.1233	State and community agencies provide financial help for disabled persons who cannot work but who need support while appealing Social Security or SSI benefit denials or while waiting for benefits to start.
(55)	2.1076	Insurance companies do not discriminate on the basis of disability.
(56)	2.0862	Employers have a positive attitude about hiring people with disabilities.

In general, the needs described as most important are those with which respondents are *least* satisfied. (See Tables 36 and 37.) That is, respondents are least satisfied with regard to their most important needs (discrimination in health insurance, for example) and most satisfied with regard to the needs they characterize as less important (such as voting by absentee ballot).

Table 38 shows the relative number of respondents who addressed various areas of concern in their written comments. Since the part of the questionnaire that solicited written comments was open-ended (i.e., respondents were asked, "Please feel free to write any additional comments below"), the relative number of respondents mentioning a particular area of concern provides a good indication of the importance of that concern. Among all the broad themes that we identified in the comments, health care emerged with the greatest frequency. Many respondents are also frustrated with the complex and often protracted process of applying for and obtaining government benefits. Educational and employment concerns were also repeatedly voiced, as was the need for information on the services available to individuals with disabilities.

Table 38
Key Themes in Written Comments

Theme	% of respondents who discussed theme[a]
Education[b]	17.4%
Accommodations in the schools	1.8%
School teachers, administrators and/or counselors	15.2%
Support services in the schools	4.6%
Employment	17.0%
Career Counseling	2.0%
Employment discrimination	4.4%
Employment disincentives	1.8%
Employment opportunities	8.8%
Vocational rehabilitation	5.1%
General	n/a
Accessibility concerns	7.7%
Basic needs (food, clothing, and shelter) and making ends meet	4.9%
Location (rural vs. urban) services	3.5%
Need for information	11.9%
Specific disabilities not recognized or getting necessary support	4.2%
Support and sensitivity training	6.2%
Transportation	6.6%
Government benefits	20.8%
Bureaucracy of obtaining government benefits	9.3%
Eligibility rules for government financial support	12.6%
Health-related concerns	40.0%
Community-based services and attendant care	16.3%
Eye care and/or dental care	3.8%
Health care coverage	12.1%
Health care providers	10.6%
Medical supplies	5.5%
Prescription medication	8.4%
Residential facilities for individuals with disabilities	6.6%
Respite care	3.3%

[a] The sample is limited to respondents who provided written comments. As previously noted, 453 surveys (40% of those returned to us or completed online) included written comments.

[b] The percentages provided for each general heading reflect the proportion of respondents who indicated a specific concerns for each of the sub-headings indicated. For example, 17.4% of respondents had concerns regarding accommodations in the schools, support services in the schools, or school teachers, administrators, and counselors.

It is also worth mentioning that those needs of special importance primarily to a specific subgroup of respondents are generally rated less important overall. For example, non-discrimination in the schools is of only moderate importance to most respondents. It was of great importance among those with developmental disabilities such as mental retardation (and among those completing the survey on their behalf), however. While concerns about health care emerged with the greatest frequency in the written comments, this is expected given that health care needs affect *all* individuals with disabilities. Meanwhile, educational or employment concerns are likely to be more pressing only for certain segments of the disabled population (i.e. those enrolled in school and/or seeking employment).

As this report demonstrates, individuals with disabilities have a wide range of legitimate grievances and concerns. Given limited funds, we suggest (1) strengthening those programs which elicited favorable comments from respondents and (2) focusing on those changes which address respondents' most important needs and/or appear to offer the greatest likelihood of success. Specifically, we recommend that the State of Oklahoma work with other governmental, commercial, nonprofit, and advocacy organizations to

- ensure full participation in SoonerStart among eligible residents, and provide adequate funding to meet the increased demand
- evaluate the cost-effectiveness of the Habilitation Training Specialist program, with efforts to increase the proportion of funding that is paid to the caregivers themselves
- ensure better monitoring and supervision of long-term residential care facilities
- ask government health agencies to consider the purchase (rather than rental) of medical equipment for in-home use
- ensure that individuals with disabilities are provided with clear, consistent, up-to-date literature describing the benefits and services available to them as well as the relevant regulations and application procedures
- ensure that teachers and school administrators are aware of their obligations to students with disabilities, and of the most effective means of meeting those obligations.

These suggestions are, at best, only part of the solution, however. In their written comments, many individuals with disabilities described enduring and difficult struggles to meet even their most basic needs — food, shelter, education, and medical care. A number of respondents chronicled long and draining battles they had fought (or were fighting) to obtain government benefits and services for themselves or their loved ones. Many of their comments amounted to pleas for assistance. Given the severity of the problems facing individuals with disabilities in Oklahoma, effective solutions are likely to require a long-term commitment of resources and a real sense of responsibility on the part of political, business, and cultural leaders throughout the state.

References

Centers for Medicare and Medicaid Services. 2002. *Americans with Disabilities Act / Olmstead Decision*. Baltimore, Maryland: Centers for Medicare and Medicaid Services. Available at http://www.hcfa.gov/medicaid/olmstead/olmshome.htm

Davis, Sharon, with Alan Abeson and June C. Lloyd. 1997. *A Status Report to the Nation on People with Mental Retardation Waiting for Community Services*. Silver Spring, Maryland: The ARC (Association of Retarded Citizens). Available at http://www.thearc.org/misc/WaitPage.html

Dunbar, Jennifer L., Harvey I. Sloane, and Curt D. Mueller. 1999. *Implementation of the State Children's Health Insurance Program: Outreach, Enrollment, and Provider Participation in Rural Areas*. Bethesda, Maryland: Project HOPE Walsh Center for Rural Health Analysis.

Internet Special Education Resources [organization]. 1999. "Parents Reaching Out in Oklahoma." In *Internet Special Education Resources*. Rockville, Maryland: Internet Special Education Resources. Available at http://www.iser.com/PRO.html

Kasprak, John and Saul Spigel. 2000. *Mental Retardation — Eligibility for Services*. Hartford: Connecticut General Assembly, Office of Legislative Research. Available at http://www.cga.state.ct.us/2000/rpt/olr/htm/2000-r-0948.htm

Listen-Up! [organization]. 2002. "ASL, SEE Sign, & Signed English." In *The Listen-Up Web*. San Antonio, Texas: Listen-Up! Available at http://www.listen-up.org/sign2.htm

National Institute on Deafness and Other Communication Disorders. 1999. *Waardenburg Syndrome: Quick Facts*. Bethesda, Maryland: National Institute on Deafness and Other Communication Disorders. Available at http://www.nidcd.nih.gov/health/pubs_hb/waard.htm

Oklahoma Commission for Rehabilitation Services. 2001. *Oklahoma Disability Resource Guide*. Oklahoma City: Oklahoma Commission for Rehabilitative Services.

Oklahoma Department of Human Services. 1999. "Administration." In *FY99 Annual Report*. Oklahoma City: Oklahoma Department of Human Services. Available at http://www.okdhs.org/ifinance/Annual_Report/FY99/administration.htm

Oklahoma Department of Human Services. 2002a. *OKDHS Policy Online*. Oklahoma City: Oklahoma Department of Human Services. Available at http://www.policy.okdhs.org/home/

Oklahoma Department of Human Services. 2002b. *Programs & Services*. Oklahoma City: Oklahoma Department of Human Services. Available at http://www.okdhs.org/programs/programs.htm

OKDHS-DDSD (Oklahoma Department of Human Services, Developmental Disabilities Services Division). 2002a. *History of Developmental Disabilities Services in Oklahoma*. Oklahoma City: OKDHS-DDSD. Available at http://www.okdhs.org/ddsd/History%20of%20DDSD%20in%20Oklahoma.htm

OKDHS-DDSD (Oklahoma Department of Human Services, Developmental Disabilities Services Division). 2002b. *Support Services*. Oklahoma City: OKDHS-DDSD. Available at http://www.okdhs.org/ddsd/Support%20Services.htm

Oklahoma Department of Rehabilitation Services, Public Information Office. 2001. *Oklahoma Disability Resource Guide*. Oklahoma City: Oklahoma Department of Rehabilitation Services.

Oklahoma Department of Rehabilitation Services. 2002. *DRS Services —Vocational Rehabilitation*. Oklahoma City: Oklahoma Department of Rehabilitation Services. Available at http://www.okrehab.org/services_vrservices.shtml

Oklahoma Health Care Authority. 2002. *Home and Community Based Services (HCBS) Waivers*. Oklahoma City: Oklahoma Health Care Authority. Available at http://www.ohca.state.ok.us/Consumer/Medicaid/Overview/

Oklahoma State Department of Health. 2002. *Eldercare Service*. Oklahoma City: Oklahoma State Department of Health. Available at http://www.health.state.ok.us/PROGRAM/eldercare/

U.S. Census Bureau. 2001. *Current Population Reports. P-60-213. Money Income in the United States: 2000*. Washington: U.S. Census Bureau.

U.S. Social Security Administration. 2002. *Social Security: What You Need To Know When You Get Disability Benefits*. Publication no. 05-10153. Washington: U.S. Social Security Administration. Available at http://www.ssa.gov/pubs/10153.html

WETA [television station]. 2002. "Individualized Education Programs & IDEA 97." In *LDOnLine*. Arlington, Virginia: WETA. Available at http://www.ldonline.org/ld_indepth/iep/idea97.html

Appendix A: Sample Cover Letter

Hello!

Please don't throw away this survey!

This survey is being mailed to you from [name of organization]. The [name of organization] has NOT released your name to anyone (including the sponsors of the research project), but the organization is distributing these surveys in support of a research project sponsored by the University of Oklahoma and the State Office of Handicapped Concerns.

The enclosed survey is for individuals with disabilities, their close relatives and/or personal caregivers. You must be 18 years of age or older to participate in this study.

Participation in this study is totally voluntary and you may refuse to answer questions or withdraw at any time. At the same time, we would be very grateful if you would take the time to respond to the enclosed questionnaire and return it within 8 weeks.

Your input is crucial for the design and implementation of programs and services that can better meet the needs of individuals with disabilities in the state of Oklahoma.

Thank you very much!

Oklahoma Office of Handicapped Concerns
(1-800-522-8224)

Appendix B: Copy of Director's Survey

Oklahoma Office of Handicapped Concerns: 2001-2002 Disability Assessment Study
Survey for Directors and/or Presidents of Organizations that Serve Individuals with Disabilities

SURVEY INSTRUCTIONS
[PLEASE NOTE: THIS SURVEY IS DOUBLE-SIDED!]

ONE: This research is being conducted under the auspices of the University of Oklahoma-Norman Campus and is funded by the Oklahoma Office of Handicapped Concerns (OHC). Your participation in this study is strictly voluntary and the results of this project will be used by state and local agencies to design policies and programs that effectively meet the needs of individuals with disabilities. All the data that we gather will remain confidential and we will never attempt to link any of the responses to any individual and/or family member. There are no foreseeable risks to you for participating in this study and this questionnaire provides an opportunity for you to express your concerns. The principal investigator for this project is Dr. Esther Wilder, Assistant Professor of Sociology at the University of Oklahoma. If you have any questions or you need any assistance filling out this survey, please do not hesitate to contact the Office of Handicapped Concerns (1-800-522-8224) or Dr. Wilder (405-325-2820) and we will do whatever we can to help you. You may obtain a copy of this survey in large print, Braille or audio format from the Office of Handicapped Concerns. You may also access and complete this survey online at: http://liaisons.oulan.ou.edu/projects/das/

TWO: The enclosed survey is designed for directors/presidents of organizations that provide services to individuals with disabilities. You must be 18 years of age or older to complete this survey. If you are not the director and/or president of such an organization, please try to pass this survey on to someone you know who can appropriately complete it.

THREE: Part II of this survey (pages 3-4) should only be filled out by directors/presidents who themselves have disabilities, are closely related to individuals with disabilities, or who serve as personal caregivers for disabled individuals. For the purposes of this survey, an individual is considered to have a "disability" if s/he has a physical or mental impairment that substantially limits one or more major life activities, has a record of such impairment, or is regarded as having such an impairment**.**

FOUR: As part of our research project, we are also distributing surveys to individuals with disabilities and their families. Those surveys contain the same questions that are included in this questionnaire. If you have already filled out one of those surveys (either on-line or on paper), please do not complete this survey. **If you have a disability and are the director of an organization that serves disabled individuals, we would prefer that you fill out this survey only**. You may, however, request and fill out additional surveys if you are related to more than one individual with a disability (for example, if you have two children with disabilities). At the same time, only one survey should be filled out for each individual with a disability. Our questionnaire for individuals with disabilities and their relatives is also available at: http://liaisons.oulan.ou.edu/projects/das/ [You may also contact the Office of Handicapped Concerns (1-800-522-8224) or Dr. Esther Wilder (405-325-2820) for a copy of this survey.]

FIVE: The survey was designed to find out how important a need or concern is to you and how satisfied you are about the way that need or concern is being addressed. For our needs assessment questions, there are two answer columns on the right side of each page. In the first column you fill in the circle (1 to 5) which best indicates how important each need is to you. In the second column, fill in the circle (1 to 5) which best tells how satisfied you are about the way that need is being met. Here's an example:

	How IMPORTANT is it to you that...					HOW SATISFIED are you that...				
	Not Important...			Very Important...		Not satisfied...			Very satisfied...	
1. You can get good medical care.	○	○	○	○	●	○	○	●	○	○
	1	2	3	4	5	1	2	3	4	5

Read the questions like this: "How IMPORTANT is it to you that you can get good medical care?" and "How SATISFIED are you that you can get good medical care?" In the example shown, the ability to get good medical care is rated "very important," while only "moderate" satisfaction is shown with the way this need is being met.

SIX: This survey contains 66 questions (plus 22 questions specifically for individuals with disabilities, their relatives and/or personal caregivers) and OHC would be grateful if you would answer all those that apply to you**.** You are also welcome to voice any disability-related concerns you have in-person or via phone (405-325-2820) to the researcher(s) (whether or not you complete this survey). You may refuse to participate, refuse to answer any question(s) or withdraw at any time without risk of loss of benefits or any penalty. You may contact the University of Oklahoma's Office of Research Administration (ORA) at 405-325-4757 or irb@ou.edu for any questions you have concerning your rights as a research participant. Please return the survey to the Office of Handicapped Concerns using the enclosed postage-free envelope. Your return of this survey (and/or your volunteering of any comments) indicates your consent to the guidelines stated above.

Oklahoma Office of Handicapped Concerns: 2001-2002 Disability Assessment Study
Part I: Information on Directors/Presidents and Organizations

1. Which of the following disabilities does your organization serve?

a. ○ Visual
b. ○ Hearing
c. ○ Mobility
d. ○ Neurological
e. ○ Psychological
f. ○ Speech
g. ○ Learning
h. ○ Mental Retardation
i. ○ Chronic Illnesses
j. ○ Other disabilities
k. ○ All disabilities

2. Are you the president or the director of the organization in question?

a. ○ President
b. ○ Director
c. ○ President and Director

3. How would you characterize the disability organization that you direct/preside over?

a ○ Small. (25 or fewer members who regularly participate or seek assistance on a monthly basis.)
b. ○ Medium. (Between 25 to 75 members who regularly participate or seek assistance on a monthly basis.)
c. ○ Large. (75 or more members who regularly participate or seek assistance on a monthly basis.)

4. Is your position as director/ president an elected position?

a. ○ No
b. ○ Yes

5. Is your position as director/ president paid?
(<u>Please check only one</u>.)

a. ○ No
b. ○ Yes, I receive a stipend.
c. ○ Yes, it is a part-time position.
d. ○ Yes, it is a full-time position.

6. Do you have a disability?

a. ○ No
b. ○ Yes

7. How many years have you served as president/director for organizations that service individuals with disabilities?

____

8. In what county is the disability organization that you currently direct/preside over located?

____

9. What is your sex?

a. ○ Male
b. ○ Female

<u>Before you proceed, please tell us the following!</u>
(<u>Please select only one response</u>.)

Who are you?

a. ○ In addition to being the director/president of an organization, I am an individual with a disability completing this questionnaire entirely on my own.
b. ○ In addition to being the director/president of an organization, I am an individual with a disability and someone is helping me to complete this questionnaire.
c. ○ In addition to being the director/president of an organization, I am the parent of a child with a disability.
d. ○ In addition to being the director/president of an organization, I am the close relative of an individual with a disability.
e. ○ In addition to being the director/president of an organization, I am the personal caregiver for an individual with a disability.
f. ○ I am the director of an organization but I do not have a disability, am not closely related to anyone who has a disability nor am I the personal caregiver for a disabled individual. (If so, skip to page 5).

NOTE: IF YOU HAVE A DISABILITY PLEASE ANSWER THE QUESTIONS ON THE FOLLOWING TWO PAGES FOR YOURSELF. IF YOU ARE CLOSELY RELATED TO SOMEONE WHO HAS A DISABILITY OR YOU SERVE AS THE PERSONAL CAREGIVER FOR A DISABLED INDIVIDUAL, PLEASE ANSWER THE QUESTIONS ON THE NEXT TWO PAGES WITH ONE SPECIFIC INDIVIDUAL IN MIND.

Oklahoma Office of Handicapped Concerns: 2001-2002 Disability Assessment Study
Part II: Demographic Information

NOTE: ALL QUESTIONS BELOW REFER <u>ONLY</u> TO INDIVIDUALS WITH DISABILITIES.
If you are the caregiver for a disabled individual or you are answering on behalf of a disabled relative or child, please answer the questions below as if you were the individual with the disability.

1. What is your disability? (<u>Check all that apply</u>.)

a. ○ Visual Impairment
b. ○ Hearing Impairment
c. ○ Mobility Impairment
d. ○ Neurological Disability
e. ○ Psychological Disability
f. ○ Speech Impairment
g. ○ Learning Disability
h. ○ Mental Retardation
i. ○ Chronic Illness
j. ○ Other

2. What is your current age?

____

3. Please indicate the <u>single</u> race or ethnicity that you most closely identify with:

a. ○ White/Caucasian
b. ○ Black/African American
c. ○ Indian/Native American
d. ○ Asian or Pacific Islander
e. ○ Hispanic/Latino/Latina

4. What is your sex?

a. ○ Male
b. ○ Female

5. Were you born in the U.S.?

a. ○ No
b. ○ Yes

6. What was your total personal income in 2000?

a. ○ None
b. ○ Less than $5,000
c. ○ $5,000 to $9,999
d. ○ $10,000 to $14,999
e. ○ $15,000 to $24,999
f. ○ $25,000 to $34,999
g. ○ $35,000 to $44,999
h. ○ $45,000 to $54,999
i. ○ $55,000 to $74,999
j. ○ $75,000 to $99,999
k. ○ $100,000 or more

7. What was your total family income in 2000?

a. ○ None
b. ○ Less than $5,000
c. ○ $5,000 to $9,999
d. ○ $10,000 to $14,999
e. ○ $15,000 to $24,999
f. ○ $25,000 to $34,999
g. ○ $35,000 to $44,999
h. ○ $45,000 to $54,999
i. ○ $55,000 to $74,999
j. ○ $75,000 to $99,999
k. ○ $100,000 or more

8. How many people are in your immediate family, including yourself?

____

9. Do you have any children?

a. ○ No
b. ○ Yes

10. What is your marital status?

a. ○ Single (never married)
b. ○ Engaged
c. ○ First marriage
d. ○ Second or subsequent marriage
e. ○ Currently divorced
f. ○ Separated
g. ○ Widowed
h. ○ Other

11. What is your highest level of educational attainment?

a. ○ Less than high school
b. ○ High school graduate
c. ○ Some college
d. ○ Associate's/Technical degree
e. ○ Four-year degree
f. ○ Some post-graduate education
g. ○ Graduate degree

12. Are you currently enrolled in school?

a. ○ No
b. ○ Yes

13. If currently enrolled in school, what grade or level of school are you in?

____

14. Which of the following best describes your residence? (<u>Please select only one.</u>)

a. ○ Rural
b. ○ Suburban
c. ○ Urban

15. Which of the following is your current living arrangement?

a. ○ Handicapped housing
b. ○ Owned house
c. ○ Owned apartment/duplex
d. ○ Rented home
e. ○ Rented apartment/duplex
f. ○ Dorm room
g. ○ Nursing home
h. ○ State institution
i. ○ Other

16. With whom do you currently live? (<u>Check all that apply</u>.)

a. ○ Alone
b. ○ With non-related individual(s)
c. ○ With spouse/significant other
d. ○ With child/children
e. ○ With parent(s)
f. ○ With sibling(s)
g. ○ With other relative(s)
h. ○ With personal care attendant
i. ○ With other(s)

17. What county do you currently reside in?

____

Oklahoma Office of Handicapped Concerns: 2001-2002 Disability Assessment Study
Part II: Demographic Information

NOTE: ALL QUESTIONS BELOW REFER ONLY TO INDIVIDUALS WITH DISABILITIES.
If you are the caregiver for a disabled individual or you are answering on behalf of a disabled relative or child, please answer the questions below as if you were the individual with the disability.

18. Do you currently receive any of the following forms of financial or governmental assistance? (Check all that apply.)

a. ○ Social Security Retirement
b. ○ Social Security Disability
c. ○ Supplemental Security Income (SSI)
d. ○ Vocational Rehabilitation
e. ○ Worker's Compensation
f. ○ Food stamps
g. ○ Medicaid
h. ○ Medicare
i. ○ Other

19. Are you currently employed?

a. ○ No (but currently seeking employment)
b. ○ No (but NOT currently seeking employment)
c. ○ Yes

21. How many hours do you you currently work per week?

a. ○ 5 or less
b. ○ 6-15
c. ○ 16-29
d. ○ 30 or more
e. ○ Not currently working

20. If currently working, which of the following categories best represents your current job?

a. ○ Managerial or Administrative Occupations
b. ○ Professional, Paraprofessional and Technical Occupations (systems analyst, teacher, human service worker, etc.)
c. ○ Sales and Related Occupations
d. ○ Clerical and Administrative Support
e. ○ Service Occupations (dental assistant, cook, fire fighter, childcare worker, etc.)
f. ○ Agriculture, Forestry, Fishing and Related Occupations (carpenter, truck driver, etc.)
g. ○ Not currently working

22. ACTIVITIES OF DAILY LIVING. For each of the following activities, please fill in one circle for each activity to indicate whether you are:

I = Independent (you don't need any help from another person)
PD = Partially Dependent (you need some help)
D = Dependent (someone else must do it for you)
C = Cannot do (even with help)
DA = Doesn't Apply

		I	PD	D	C	DA
a.	**Eating**	○	○	○	○	○
b.	**Dressing**	○	○	○	○	○
c.	**Personal hygiene**	○	○	○	○	○
d.	**Walking**	○	○	○	○	○
e.	**Writing**	○	○	○	○	○
f.	**Typing**	○	○	○	○	○
g.	**Telephone use**	○	○	○	○	○
h.	**Day to day communication**	○	○	○	○	○
i.	**Cooking**	○	○	○	○	○
j.	**Driving**	○	○	○	○	○
k.	**Housekeeping**	○	○	○	○	○
l.	**Bowel program**	○	○	○	○	○
m.	**Bladder program**	○	○	○	○	○
n.	**Wheelchair use**	○	○	○	○	○
o.	**Transfers**	○	○	○	○	○

Oklahoma Office of Handicapped Concerns: 2001-2002 Disability Assessment Study
Part III: Needs Assessment

	How IMPORTANT is it to you that...					**HOW SATISFIED are you that...**				
	Not Important...			**Very Important...**		**Not satisfied...**			**Very satisfied...**	
1. A central information and referral service is available for disabled persons and their families.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
2. Programs and services designed to serve the disabled community are provided by individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
3. Accessible homes and apartments are available in your community.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
4. Buildings, parks, businesses and pedestrian areas are accessible to persons with all kinds of disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
5. Public transportation allows individuals with disabilities to go where they need to go.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
6. Public transportation (for disabled individuals) operates during convenient hours.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
7. Handicapped parking ordinances are strictly enforced.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
8. There is strict enforcement of the Americans with Disabilities Act.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
9. Support groups are available to disabled persons and their families.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
10. A variety of social and recreational activities are available for disabled children and adults.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
11. Day care programs are available for disabled children.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
12. Disabled children can get the services and care they need early enough to improve their opportunities in life.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
13. Nursing care is available to individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
14. Good quality attendant care is available.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
15. Assistance in learning new ways to accomplish daily tasks is available to individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
16. Temporary care (respite and/or attendant care) is available to ease the burden on regular caregivers.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5

Oklahoma Office of Handicapped Concerns: 2001-2002 Disability Assessment Study
Part III: Needs Assessment

	How IMPORTANT is it to you that...					**HOW SATISFIED are you that...**				
	Not Important...			**Very Important...**		**Not satisfied...**			**Very satisfied...**	
17. Financial help is available to make a home or apartment accessible for individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
18. Financial help is available for needed adaptive aids and equipment for individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
19. Financial help is available for housekeeping assistance for individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
20. Financial help is available for chore services (shopping, lawn care, etc.) for individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
21. Financial help is available for qualified attendant care.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
22. Personal aides are sensitive to the needs of individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
23. Affordable prescription drugs are available to individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
24. Housing rental assistance is available for disabled individuals when needed.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
25. Insurance companies do not discriminate on the basis of disability.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
26. Nursing home care is responsive to the needs of individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
27. There is adequate support for independent living for disabled individuals who wish to avoid institutionalization.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
28. Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for routine medical care (doctor visits, etc.).	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
29. Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for emergency medical procedures and surgery.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
30. Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for medical supplies (wheelchairs, hearing aids, etc.).	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5

Oklahoma Office of Handicapped Concerns: 2001-2002 Disability Assessment Study
Part III: Needs Assessment

	How IMPORTANT is it to you that...					**HOW SATISFIED are you that...**				
	Not Important...			**Very Important...**		**Not satisfied...**			**Very satisfied...**	
31. Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for attendant care.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
32. Government health insurance programs (Medicare, Medicaid, etc.) provide adequate coverage for prescription drugs.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
33. Utility bills are affordable.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
34. Social Security Disability Insurance and Supplemental Security Income (SSI) provide adequate financial help to disabled individuals who cannot work.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
35. State and community agencies provide financial help for disabled persons who cannot work but who need support while appealing Social Security or SSI benefit denials or while waiting for benefits to start.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
36. Good career counseling is available for disabled persons.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
37. Vocational rehabilitation provides disabled individuals with the training they need to obtain meaningful employment.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
38. Good job placement help is available from state rehabilitation and employment agencies and from other employment programs.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
39. Disabled persons have adequate opportunities to change jobs or advance in their careers.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
40. A variety of job opportunities are available for disabled persons.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
41. Employers have a positive attitude about hiring people with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
42. *Employed* individuals with disabilities have adequate financial support from state and local agencies.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
43. Workplaces provide reasonable accommodations for individuals with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5

Oklahoma Office of Handicapped Concerns: 2001-2002 Disability Assessment Study
Part III: Needs Assessment

	How IMPORTANT is it to you that...					**HOW SATISFIED are you that...**				
	Not Important...			**Very Important...**		**Not satisfied...**			**Very satisfied...**	
44. Mental health and health care providers are sensitive to the needs of persons with disabilities.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
45. Group homes for mentally and physically disabled children are available in your community.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
46. Effective academic programs are available for disabled students.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
47. Disabled students can participate in the extra-curricular activities offered by their schools.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
48. Adaptive educational materials and needed support services (i.e. speech therapists, translators, etc.) are readily available to disabled students.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
49. Training is available to teach disabled people and parents of disabled children how to advocate for their rights.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
50. School administrators and teachers are sensitive to the needs of disabled students.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
51. Affordable legal help is available to disabled persons who file Social Security appeals, discrimination cases, etc.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
52. Disabled persons can vote easily at regular polling places.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
53. Disabled persons can vote by absentee ballot when necessary.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
54. Police and other officials are sensitive to the needs of disabled persons.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
55. The media portray disabled people in realistic ways.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5
56. The media portray disabled people in a positive light.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 1	○ 2	○ 3	○ 4	○ 5

Please feel free to write any additional comments below.

Appendix C: Survey Distribution

Using the January 2001 *Oklahoma Disability Resource Guide* of the Oklahoma Department of Rehabilitation Services, we identified over 100 disability-related organizations and mailed out 116 surveys directly to presidents and directors of these groups. (Approximately twelve of these were returned due to incorrect addresses or names.) In addition, we telephoned over 50 organizations to request assistance (i.e., mailing lists) in order to distribute questionnaires to individuals with disabilities, the close relatives of individuals with disabilities, and the personal caregivers of individuals with disabilities. With few exceptions, the staff of these organizations were supportive of our project and expressed a willingness to help us reach our target population. Because of the need to protect the privacy of their clients, however, many of the organizations would not release mailing lists but instead requested that we provide them with surveys in pre-stamped envelopes, which they then mailed to their clients on our behalf.

The list on the next page enumerates the organizations that agreed to work with us. It also indicates the number of surveys each agreed to distribute on our behalf (or the total number of people on the mailing list that the organization provided to us). I have also noted whether (1) the organization provided us with a mailing list, (2) the organization agreed to mail out surveys to individuals on its mailing list, or (3) the organization agreed to distribute surveys by hand to its clients and members. In brackets I have also indicated how many surveys were returned to the survey team as undeliverable (wrong address, deceased addressee, etc.).

In addition to contacting organizations, we also distributed a press release to the Oklahoma Press Association which was subsequently circulated to local newspapers throughout the state. The following newspapers included some, if not all, of the information provided in the press release: the American Weekly (9/4/01); the Bristow News & Record-Citizen (9/7/01); the Cleveland American (8/29/01); the Clinton Oklahoma Daily News (9/16/01); the Durant Bryan County Star (8/30/01); the Frederick Leader (8/26/01); the Gage Record (8/30/01); the Prague Times-Herald (9/6/01); the Morris News (8/30/01); the Ryan Leader (8/30/01); and the Wilburton Latimer News-Tribune (9/6/01). The press release included the toll-free number of the Office of Handicapped Concerns as well as the web address for the online version of the survey so that potential subjects would be able to participate in our study. Moreover, an announcement about our study appeared in the newsletter of the Oklahoma Office of Handicapped Concerns. Their website (http://www.state.ok.us/~ohc/) included a press-release about our study as well as a link to the survey itself.

We also contacted several local television stations about the study. These included KWTV (Channel 9, CBS affiliate, OKC), KOCO (Channel 5, ABC affiliate, OKC), KOKI (Channel 23, Fox affiliate, Tulsa), KJRH (Channel 2, NBC affiliate, Tulsa), KOTV (Channel 6, CBS affiliate, Tulsa), KTUL (Channel 8, ABC affiliate, Tulsa), KSWO (Channel 7, ABC affiliate, Tulsa), and KSWO (Channel 7, ABC affiliate, Lawton). Unfortunately, only KSWO responded to our request to help publicize our study. They aired a story about our project in late August on the Friday evening news.

In response to our efforts to publicize the study — especially in response to the KSWO news report — we received individual requests for approximately 150 to 200 surveys. Most inquirers requested a single survey, but eight people requested a dozen or more surveys to pass along to friends, relatives, and other individuals with disabilities. For example, one woman requested 20 surveys to be sent to the Multiple Sclerosis Society of Oklahoma City.

Finally, in November we attended the Thanksgiving celebration of "Handicapped for Christ," an organization that serves individuals with a wide range of disabilities (although most have visual impairments). Although there were over 50 people present at the celebration, less than ten requested copies of our survey. As a professor at the University of Oklahoma I also discussed my research in my classes, and a handful of students requested surveys.

Cooperating Organizations:

A New Leaf, Inc (24 surveys, organization mailed out)
A.S.K (Ambucs + Share for Life + Komputer) (300 surveys, organization mailed out)
Abilities Galore (10 surveys, organization mailed out)
Apex, Inc. (32 Surveys, organization mailed out)
CarePoint, Inc. — Oklahoma City (300 surveys, organization mailed out) [30 undeliverable]
Cerebral Palsy and Handicapped of Oklahoma, Inc (110 Surveys, organization distributed by hand)
Chickasha Opportunity Center (34 surveys, mailing list provided)
Coalition for Federal Aviation Employees with Disabilities (50 surveys, organization mailed out)
Cystic Fibrosis Foundation — Sooner Chapter (25 Surveys, organization mailed out)
Down Syndrome Association of Tulsa (175 surveys, organization mailed out) [1 undeliverable]
Epilepsy Association of the Sooner State (100 Surveys, organization mailed out) [13 undeliverable]
Faith 7 School and Workshop (34 surveys, organization mailed out)
Green Country Independent Living Resource Center (180 surveys, organization mailed out) [13 undeliverable]
INCOR (100 surveys, organization mailed out)
Logan County Association for Retarded Citizens (New Horizons) (15 surveys, organization mailed out)
Mid-America Chapter of Paralyzed Veterans of America (100 surveys, organization distributed by hand)
Multiple Sclerosis Support Group (Altus Chapter) (7 surveys, mailing list provided)
Multiple Sclerosis Support Group (Bristow) (8 surveys, organization mailed out)
Multiple Sclerosis Support Group (Buffalo) (7 surveys, organization mailed out)
Multiple Sclerosis Support Group (Chickasha) (10 surveys, organization mailed out) [2 undeliverable]
Multiple Sclerosis Support Group (Enid/Fairview) (30 surveys, organization mailed out)
Multiple Sclerosis Support Group (Norman) (25 surveys, organization mailed out)
Muskogee Association for Retarded Citizens (17 surveys, organization mailed out)
National Federation of the Blind (198 surveys, mailing list provided)
Oklahoma Brain Injury Association (200 surveys, organization mailed out 116, distributed the remainder) [2 undeliverable]
Oklahoma City Support Group for Rare Autoimmune Diseases (29 surveys, mailing list provided)
Oklahoma Developmental Disabilities Council (87 surveys, mailing list provided)
Oklahoma Disability Law Center — OKC (1000 surveys, organization mailed out)
Oklahoma Easter Seal Society (1000 surveys, organization mailed out) [8 undeliverable]
Oklahoma Foundation for the Disabled (200 surveys, organization mailed out) [2 undeliverable]
Oklahoma Hemophilia Foundation (240 surveys, organization mailed out) [4 undeliverable]
Oklahoma League for the Blind (200 surveys, organization mailed out)
Oklahoma March of Dimes (25 surveys, organization mailed out)
Oklahoma School for the Deaf (1000 surveys, organization mailed out) [106 undeliverable]
Oklahoma Sickle Cell Disease Association (150 surveys, organization mailed out)
Oklahoma State University (OSU) Disabled Student Services (360 surveys, organization mailed out) [31 undeliverable]
Oklahomans for Independent Living (500 Surveys, organization mailed out) [49 undeliverable]
Parkinson's Disease Support Group (Ada) (100 surveys, organization mailed out) [2 undeliverable]
Parkinson's Disease Information and Referral Center (100 surveys, organization distributed by hand)
Rose State College Special Services (50 surveys, organization distributed by hand)
Scott Sabolich Prosthetic and Research Center (50 surveys, organization distributed by hand)
Spina Bifida Association of Oklahoma (500 Surveys, organization mailed out) [110 undeliverable]
Spinal Cord Injury Association of Oklahoma (262 surveys, mailing list provided)
Tulsa Center for the Physically Limited (100 surveys, organization distributed by hand)
Tulsa Speech and Hearing Association (750 surveys, organization mailed out) [88 undeliverable]

Total: 8794 surveys [461 undeliverable]

The surveys noted here as undeliverable were returned to the survey team due to incorrect addresses, deceased addressees, etc. Additional undeliverable surveys may have been returned directly to the cooperating organizations.